

## ABSTRACT

Title of Document: EMERGING FROM THE SHADOWS: A CASE STUDY  
ON THE QUALITY OF LIFE OF STUDENTS WITH  
DISABILITIES IN MONROVIA, LIBERIA

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People with disabilities are often the last group to be included in development agendas. For children with disabilities, this translates into exclusion in the educational setting with piecemeal agendas created by various governments. In Liberia, children with disabilities are not only excluded from the classroom, but the government's most recent education law singles children with disabilities out as individuals that may be excluded from the classroom. It is difficult to find research on people with disabilities in low-income countries that have experienced recent conflict. In an attempt to better understand the lives of children with disabilities in Liberia, I developed and implemented a case study that examines the lives of families with children with disabilities at an educational center in Monrovia, Liberia called The Alliance Center for Children with Disabilities<sup>1</sup>, hereafter referred to as the Center. I used Schalock and Keith's (2000) Quality of Life (QOL) Framework to gauge the influence the Center has over the lives of the families and Critical Disability Theory as a base for a discussion on societal norms and people with

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<sup>1</sup> This is a pseudonym to protect the identities of my participants and their families.

disabilities. Through intense analysis of interview transcripts, documents and observations, this study concludes that the families associated with the Center currently have a better quality of life based on the domains in Schalock and Keith's (2000) Quality of Life framework than those with children with disabilities not attending the Center.

QUALITY OF LIFE RESEARCH ON STUDENTS WITH DISABILITIES IN  
MONROVIA, LIBERIA

By

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### **Dedication**

Many, many people helped to make this research possible, both through emotional and more tangible support. However, I would like to dedicate this to the most important people in this research, the families and staff at the Alliance Center for Children with Disabilities. The people at the Center face seeming insurmountable odds, but they impressed me with their compassion and sense of purpose on a daily basis. The children at the Center will be in my heart forever and I miss my life in Liberia daily.

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## ABBREVIATIONS:

AAAS (American Academy of Arts and Sciences)

ACS (American Colonization Society)

ASL (American Sign Language)

CBR (Community Based Rehabilitation)

CRC (Convention on the Rights of the Child)

DCPS (District of Columbia Public Schools)

DFID (Department for International Development, UKAID)

EFA (Education for All)

ESP (Education Sector Plan)

GDP (Gross Domestic Product)

GOL (Government of Liberia)

ICF (International Classification of Functioning, Disability and Health)

INGO (International Non-Governmental Organization)

MOE (Ministry of Education)

NASA (National Aeronautics and Space Administration)

NGO (Non-Governmental Organization)

NPFL (National Patriotic Front of Liberia)

OECD (Organization for Economic Cooperation and Development)

PTA (Parent/Teacher Associations)

PTSD (Post-Traumatic Stress Disorder)

QOL (Quality of Life)

ROL (Republic of Liberia)

UNCRPD (United Nations Convention on the Rights of Persons with Disabilities)

UNDP (United Nations Development Programme)

UNESCO (United Nations Educational, Scientific, and Cultural Organization)

UNICEF (United Nations Children Fund)

WHO (World Health Organization)

## **Chapter One**

### **Introduction to the Research**

From the mid-20<sup>th</sup> century until now, disability rights advocates have fought hard to create an even playing field for people with disabilities. Unfortunately, this population is often one of the last groups to achieve economic equity and remains one of the most marginalized groups in the world (World Health Organization, 2011). In Liberia, people with disabilities are often stigmatized and excluded from the opportunities for economic prosperity. People with disabilities face difficulties in every aspect of their lives, from receiving basic education to finding a job. Discrimination and cultural stigma have left many people with disabilities on the edge of society, leaving them among the poorest of the poor (Filmer, 2008; Kulklys, 2005).

### **Statement of the Problem**

Creating an environment where all children are welcome in school, including those with disabilities, is a challenge for any country. As a special education teacher in Los Angeles, California, I see firsthand the exclusion and stigma students with disabilities face in a country with numerous laws protecting those students against injustice. For a country like Liberia, that has recently ended a brutal 14-year civil war, the challenge of overcoming the exclusionary practices and changing society's attitudes towards people with disabilities may seem insurmountable, perhaps even impossible. However, this does not condone the practice of putting these students at the bottom of the access list.

Research surrounding the Education for All (EFA) goals has brought to light the plight of various marginalized groups (see Peters, 2003; United Nations Educational, Scientific, and Cultural Organization (UNESCO), 2010). While many governments are making strides in improving education access for some populations, such as girls (UNESCO, 2011a), children with disabilities are usually the last group to receive equitable treatment, and adults with disabilities are often left without a voice in the development process (Mitra, Posarac & Vick, 2013). The World Health Organization (WHO) (2011) stated, “The correlation for both children and adults between low educational outcomes and having a disability is often stronger than the correlations between low education outcome and other characteristics...” (p. 206). The correlation could be for various reasons, from the type of disability and services available in country to the stigma of disabilities, which has led to the exclusion of people with any disability, mild to severe.

Liberia is a country in West Africa that is in post-conflict reconstruction because of a devastating civil war, which lasted from 1989 to 2003. The country hopes to fully recover from the impact of the war and move into an era of development and prosperity soon. The opening words to the Liberian Poverty Reduction Strategy Paper (PRSP) are full of hope that the future will be peaceful with increased economic success. It states, “Liberia is on the move. After decades of economic mismanagement and fourteen years of brutal civil war, Liberia’s national nightmare is over” (Republic of Liberia (ROL), 2008, p. 13). In the most recent development strategy, called Liberia RISING 2030, The Government of Liberia (GOL) focuses on becoming a middle-income country by 2030,

“leaving no Liberian behind” (Republic of Liberia, 2009); however, children with disabilities in Liberia are routinely denied access to education and basic services.

Most children with disabilities are excluded from the classroom and the most recent special education law specifically identifies children with disabilities as students who are eligible to be excluded from free and compulsory education. Children with disabilities in Liberia, especially those with more severe disabilities, are denied access to government schools based on a clause in the most recent education law which states, “A school may exempt a child entirely, partially or conditionally from free and compulsory school attendance if it is in the best interest of the child, *especially those with disabilities* [emphasis added]” (ROL Ministry of Foreign Affairs, 2011). This clause influences the quality of life for each of these children because they are excluded from the social and human capital benefits of school in order to reach his or her full potential. Culturally, social stigma leaves them without the tools for empowerment to fight for their basic rights. If Liberia is to actually “leave no Liberian behind,” an increased focus on people with disabilities is needed.

In 2008, some of the United Nations member countries created the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which,

takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. (United Nations, n.d.)

Liberia has signed and ratified this convention, yet it is not following the basic tenets of the convention to view people with disabilities as “subjects with rights.” This research shows, not only in the most current education law, but also throughout my research on families with people with disabilities, how Liberia is leaving children with disabilities behind.

### **Research Question and Purpose**

The Alliance Center for Children with Disabilities,<sup>2</sup> hereafter referred to as the Center, grew out a void in educational opportunities for children with disabilities. David, the Center’s director, and his wife Praise have a son with cerebral palsy, Adam. David and Praise helped start a different center for children with disabilities in the refugee camp where they lived before returning to Monrovia in 2008. When David and Praise returned to Monrovia, they noticed that there was not a place for their son to attend school. David and Praise, with the help of an American non-governmental organization (NGO), started the Center. This study examines the lives of the 10 families with children over the age of six who send their children to the Center. In order to begin to respond to the difficulties of life with a disability in a developing country, I will answer the following question in my case study:

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<sup>2</sup> This is a pseudonym to protect the identities of my participants and their families.



Based on caregiver responses, and taking into account the Liberian context, how does The Alliance Center for Children with Disabilities influence the quality of life for its students and the students' families?

The purpose of this study is to determine the influence of an educational center in Monrovia that caters to children with disabilities and their families. In addition, I seek to understand the need for an exclusive school for children with disabilities, even though the international community is pushing for inclusive development.

### **Significance of the Study**

There has not been a study, to my knowledge, on the lives of people with disabilities in Liberia, especially one including those with cognitive disabilities. Worldwide, many researchers point out a void in research on people with disabilities in lower income countries. Mitra, Posarac and Vick (2013) observed, "Persons with disabilities have so far received limited attention in development research given the absence of quality data on disability" (p. 1). Filmer (2008) stated, "While there has been much discussion about policy interventions to increase access to schooling for children with disabilities...little...empirical analysis has been conducted on which to base this policy" (p. 141). In addition, the WHO (2011) acknowledged that, "there are few documents providing a compilation and analysis of the ways countries have developed policies and responses to address the needs of people with disabilities" (p. xxi). O'Sullivan and MacLachlan (2009) pointed out, "Research that accurately reflects the issue of childhood disability is imperative if effective strategies to prevent and manage childhood disability in sub-Saharan Africa are going to be implemented" (p. 166). Disability touches everyone at some point, especially in a post-conflict situation like

Liberia; yet, even in this age of information, there is a considerable lack of information on the lives of these people in developing countries.

Although this study focuses on one school, hopefully it provides a much needed, in-depth analysis of the lives of families with children with disabilities. Inferences can be made for other children that might not have a family willing or able to put the time and effort needed to educate and empower a child with a disability. After 40 interviews with a variety of parents, NGO and International Non-Governmental Organization (INGO) workers, government employees and community members, it appears that the lives of these 10 families reflect the lives of many other families who have children with disabilities; however, this is a small population and is not completely representative of the entire population of people with disabilities in Liberia.

### **Definitions**

Research with people with disabilities encounters many difficulties. From the onset, researchers can have difficulties in the very definition of the word disability. There are many connotations connected to that word and some critical researchers (Pothier & Devlin, 2006; Siebers, 2010) question all definitions of disability because it puts the focus on the disability and not the individual as a human. Keeping these criticisms in mind, I do believe that defining the terms is necessary to create a clear picture of my participants.

### **Disability**

When examining disability, the first challenge that a researcher encounters is the definition. Many researchers have difficulty with defining disability because of the sheer

number of definitions (Brown, 2003; Pothier & Devlin, 2006; WHO, 2011). In order to encompass as many aspects of disability as possible, I will define disability using The World Health Organization (2002) definition, which characterizes disability as, “the umbrella term for impairments, activity limitations and participation restrictions” (p. 2). This definition includes three major domains for disability: body functioning and structure, activities and participation, and environmental factors (WHO, 2011). Peters (2003) suggested that this definition “shifts the focus from disability as an innate deficit to disability as constructed through the interaction between the individual and the environment” (p. 12). She also pointed out that “this conceptual model of disability encourages focus on kinds and levels of interventions appropriate to the disablement needs of individuals...and is consistent with the social model of disability that is upheld by disability rights organizations and many disabled people” (p. 12). This definition fits with this research because it looks at disability as a social construct, rather than an individual manifestation.

Within the above definition, there is an important distinction between impairment and disability. Impairment is “an injury, illness, or congenital condition that causes or is likely to cause a loss or difference of physiological or psychological function” (Northern Officer Group, n.d., p. 1). Disability refers to the negative aspects of the interactions between an individual (with a health condition) and that individual’s contextual factors (environmental and personal) (WHO, 2011). Many researchers use this definition (Croft, 2010; Peters, 2003; WHO, 2002; WHO, 2011).

### **Inclusive Education**

Inclusion means more than just bringing children with disabilities into the classroom. It is a shift in the societal culture. In 1994, approximately 92 countries came together in Salamanca, Spain and developed the Salamanca Statement and Framework for Action on Special Needs Education (The Salamanca Agreement, 1994). The Salamanca Agreement defined an inclusive school as:

... [a school where] all children should learn together, wherever possible, regardless of any difficulties or differences they may have. Inclusive schools must recognize and respond to the diverse needs of their students, accommodating both different learning styles and rates of learning and ensuring quality education to all through appropriate curricula, organizational arrangements, teaching strategies, resource use and partnerships with their communities. There should be a continuum of support and services to match the continuum of special needs encountered in every school.

Inclusive schools do more than just adding ramps or ensuring that bathrooms are available and accessible. There must be a fundamental shift away from the misunderstandings and discriminatory practices of the past. Many schools continue to use a more sympathetic, open and understanding way of including children and adults with disabilities.

### **Multidimensional Poverty**

Multidimensional poverty looks at more than just income. The United Nations Development Programme (UNDP) has a multidimensional poverty index that is a more comprehensive look at poverty, examining “overlapping deprivations in health,

education, and standard of living” (United Nations Development Programme, 2013, p. 27). This comprehensive definition aligns with the quality of life idea of researching an individual holistically.

### **Descriptions of Disabilities in the Study**

There are many different types of disabilities. This section will describe the different cognitive and sensory disabilities found at the Center and present in the study. A medical doctor has not diagnosed any of the students at the Center. I chose these disabilities because they appear to be the ones that are present in many of the students based on my observations and understanding of disability through my Master’s studies and doctoral research.

#### **Cerebral Palsy**

A brain abnormality or injury to the brain during pregnancy, labor and/or delivery or just after birth causes cerebral palsy. Cerebral palsy affects motor functions and muscles (My Child Cerebral Palsy Foundation, 2013). Symptoms for cerebral palsy can be mild to severe and affect different areas of the body. There are many different variations of cerebral palsy. The most common is spastic cerebral palsy. People with this form of cerebral palsy have very tight muscles, an abnormal gait, tight joints, and muscle weakness or paralysis. Spastic cerebral palsy can affect any part of the body, one side or both, legs, arms, etc. (Kaneshiro, 2013). People with cerebral palsy can also have difficulty with vision or hearing, controlling saliva, intellectual disabilities, and/or dental problems, among other difficulties associated with the disability (Mayo Clinic, 2012).

#### **Hearing Impairments**

Hearing impairment is a spectrum of hearing ability from mild to severe and is usually referred to as “hard of hearing” (WHO, 2013). Those that have profound hearing loss are “deaf” (WHO, 2013). Hearing loss can be inherited, caused by maternal rubella or other complications at birth, meningitis, chronic ear infections, measles and mumps, head injury, excessive noise, age related or foreign bodies blocking the ear canal (WHO, 2013).

### **Autism Spectrum Disorder**

Autism is a disorder, “characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors” (Autism Speaks Inc, 2013). Autism is a spectrum disorder with symptoms from mild to severe. The National Institute of Neurological Disorders and Stroke pointed out that scientists are not completely certain about the causes of autism (National Institute of Neurological Disorders and Stroke, 2013). Some research suggested that autism is caused by many different factors including genetic predisposition, environmental factors, the age of the parents at the time of conception, mental illness and oxygen deprivation during birth (Autism Speaks Inc, 2013).

### **Epilepsy**

Epilepsy is a “central nervous system disorder...in which the nerve cell activity in [the] brain is disturbed, causing a seizure during which you experience abnormal behavior, symptoms and sensations, including loss of consciousness” (Mayo Clinic Staff, 2013). Many different events or biological factors can cause epilepsy. The Center for Disease Control and Prevention (CDC) (2013) stated, “In nearly two-thirds of the cases

of epilepsy, a specific underlying cause is not identified.” Medication, and in some cases surgery, can help reduce the amount or intensity of seizures (Mayo Clinic Staff, 2013). Epilepsy does not cause any other type of disability and children without other medical problems can have seizures. However, the Epilepsy Foundation Metropolitan New York (2013) referred to a study which found that, “children with mental retardation and cerebral palsy had a 35% chance of developing epilepsy...[and] the risk of a child with a developmental disability experiencing an unprovoked seizure...is about 4 times greater than in the general population.” A child with epilepsy can expect normal growth and function when other disabilities are not present.

### **Developmental Delay/Intellectual Disability**

An intellectual disability/developmental delay (formerly referred to as mental retardation) refers to “significant limitations both in intellectual functioning... and in adaptive behavior, which covers many everyday social and practical skills” (American Association on Intellectual and Developmental Disabilities, 2013). There are many different causes for an intellectual disability: genetic conditions, problems during pregnancy, problems at birth and health problems including whooping cough, meningitis, the measles, and extreme malnutrition or exposure to poisons like lead or mercury (National Dissemination Center for Children with Disabilities, n.d.). Children with intellectual disabilities have difficulty learning to talk, remembering things, understanding social rules or understanding the consequences for his or her actions, solving problems or thinking logically (National Dissemination Center for Children with Disabilities, n.d.). A child with an intellectual disability will be delayed in his or her

ability to sit up, crawl or walk (National Dissemination Center for Children with Disabilities, n.d.).

### **Personal Connection to the Topic**

My personal reason for choosing to study the lives of families of students with disabilities is two-fold: (1) my experience as a Special Education teacher in Washington, D.C. and knowledge of disabilities and (2) my interest in international development. During research for a class at the University of Maryland, I realized that there was not a lot of literature or on-the-ground research for people with disabilities in developing countries. The global community had developed agreements and conventions, including Education for All and the UNCRPD, but there seemed to be little focus on the plight of this population. When my advisor and another former professor began doing research in Liberia, I decided to research the country and came across the Center. I was intrigued by their apparent success and wanted to know how this institution helped students and families increase QOL, something I had not seen claimed by other organizations.

While in Liberia, I was lucky enough to volunteer at both the Center and the Ministry of Education, Division of Special Education. I did not have a passive role at either place. At the Center, I spent six hours a day, three days a week, helping in anyway I could, whether that was teaching a lesson to the students or organizing staff training on people with disabilities. At the Division of Special Education, I researched different programs for special education teachers in Africa and helped to develop a five-year plan for the Division. My volunteer activities provided me inside access to the successes and challenges in the Division of Special Education. At the Center, I was able to spend an



extended period with the students, meet the parents on more than one occasion and understand the difficulties each family faced.

### **Organization of the Study**

My dissertation is separated into chapters. Chapter 1 has served as an introduction to the problem, Liberia, my research and the organization of my dissertation. Chapter 2 reviews relevant literature, theories and the Quality of Life (QOL) framework. Chapter 3 provides in-depth context of Liberia. In chapter 4, I discuss the case study methodology. In chapter 5, I present my findings in profiles of each student. In chapter 6, I analyze the influence of the Center on the families with reference to the Liberians' context. In my last chapter, chapter 7, I provide an analysis of the challenges the families face to integration in their communities through a critical lens, present my conclusions and give recommendations for the Center and for policy changes in Liberia.

### **Chapter Summary**

Development agencies, research institutions, governments and family members often neglect children with disabilities. They are seen as bewitched, too small of a population to be concerned about, invisible on the global stage. The purpose of this chapter was to introduce some of the major issues children with disabilities face, as well as give a brief overview for the layout of the subsequent chapters. Children with disabilities have been overlooked long enough. They deserve the same focus and research that is changing the way educational programs are evolving for all children. In 1976, Hubert H. Humphrey stated, "The moral test of a government is how it treats those who are at the dawn of life, the children; those who are in the twilight of life, the aged;

and those who are in the shadow of life, the sick, the needy, and the handicapped”

(University of Minnesota, 2013). This quote could be extended to include the moral test for anyone. This chapter is the introduction to the problems this research seeks to understand.

## **Chapter Two**

### **Literature on Disability: Critical Disability Theory and Quality of Life Research**

Everyone has experienced disability, whether it is temporary, due to surgery or a broken bone, or permanent as in intellectual disabilities or cerebral palsy. According to the World Health Organization (2013), approximately 15 percent of the world's population is living with a disability. Of that 15 percent, 80 percent reside in developing countries (Barron & Ncube, 2010, p. 36). However, the prevalence of disability is often miscalculated because families often will hide a member with a disability due to social stigma (Braithwaite, Carroll, Mont & Peffley, 2008). Mont (2007) found that, "Reported disability prevalence rates from around the world vary dramatically, for example from under 1% in Kenya and Bangladesh to 20% in New Zealand" (p. 1). These drastically different numbers illustrate the difficulty in obtaining reliable data on people with disabilities across the world. This also makes it very difficult for needed services to be determined or present services to be analyzed, let alone offered and set in place.

### **Global Disability**

In 2008, the UNCPRD came into existence, with 155 countries having signed and 132 countries having ratified the Convention as of July 1, 2013 (United Nations, n.d). The purpose of the Convention was to, "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (United Nations, 2006, Article 1, purpose). Shakespeare (2012) pointed out that the UNCPRD marked an end to the first phase of the disability rights movement in many higher income countries because there is

now, “a generation of people with disabilities who have grown up expecting access to education, employment and community participation” (p. 271). In many lower income countries, such as Liberia, that have signed and ratified the UNCRPD, there is little to no policy, so people with disabilities remain an ignored part of the development process (Grech, 2008; Shakespeare, 2012). Mitra *et al.* (2013) found, “...as a group, persons with disabilities, on average, experience multiple deprivations at higher rates and in higher breadth, depth, and severity than persons without disabilities...” (p. 11). The same study suggested, “...that persons with disabilities should be explicitly incorporated in policymaking and research agendas related to poverty in developing countries” (p. 11). Although many developing countries ratified the UNCRPD, implementation of the Convention has been slow in coming.

People with disabilities are most often disproportionately the poorest of the poor in most countries (Braithwaite *et al.*, 2008; Filmer, 2008; Kuklys, 2005; Mitra *et al.*, 2013). In Uganda, Hoogeveen (2005) stated, “The estimates show that 27% of the urban dwellers are poor and the poverty amongst those who live in a household with a disabled head is much higher, 43%” (p. 605). This is not just limited to developing countries. In the UK, Kuklys (2005) found that, “Poverty rates among households with disabled members increase by about 50% when adjusting for the effect of disability in the welfare measure” (p. 75-76). Interestingly, Mitra *et al.* (2013) found that, “...gaps in economic well-being and poverty were found to be more significant and larger in middle income countries compared to low income countries” (p. 11). The authors suggest that further research is needed to connect economic development, poverty and disability. If a majority of a population in a country lives in extreme poverty and development strategies do not

aim to create an inclusive environment, the conclusion that people with disabilities are left behind during the growth process is not a hard leap to make. Shakespeare (2012) referred to the working paper version of Mitra *et al.* (2013) when he suggested, “This is not to say that disabled people are not poor in low-income countries, only to say that so is everyone else” (p. 277). This increasingly marginalized population is continually the last to receive the economic benefits of the global reduction in poverty. It cannot be a coincidence that in countries across the world, people with disabilities are more likely to end up at the lower end of the economic ladder.

Although there are many health-related factors that cause disabilities, Mitra *et al.* (2013) stated “poverty... [increases] the likelihood that a health condition may result in a disability...” (p. 2). The Department for International Development (DFID)(2000) reported, “As many as 50% of disabilities are preventable and directly linked to poverty” (p. 3). In Vietnam, Mont and Viet Cuong (2011) found that, “Disability...is significantly correlated with poverty... [and] after accounting for the extra costs of disability, the correlation is stronger...” (p. 339). Research shows that poverty can cause disabilities through the lack of adequate preventive care and differentiation in additional cost of treatment once a person has a disability, which could result in further disablement or a worsened disability (Kuklys, 2005; Mitra *et al.*, 2013; Mont & Viet Cuong, 2011). Although disability is sometimes preventable, and research shows a correlation between poverty and disability (DFID, 2000; Kuklys, 2005; Mitra *et al.*, 2013; Mont & Viet Cuong, 2011; Shakespeare, 2012), there is still a lack of focus on the needs of this population.

### **Education and Disability**

Education is a way out of poverty. Croft (2012) pointed out, “Education is...thought to have the potential to contribute to breaking the connection between disability and poverty, but, conversely, to exacerbate poverty where it excludes disabled people” (p. 2). Filmer (2008) found in his study of 14 household surveys that, “...ensuring that youth with disabilities do not have lower educational attainment could be a powerful way to reduce the likelihood that they live in poverty as adults” (p. 150). The continued exclusion of children with disabilities in many countries is simply continuing the cycle of poverty for the poorest of the poor.

The numbers on children, worldwide, with disabilities varies depending on the source. One reason for this is the lack of accurate census data. The WHO (2011) estimates that the number of children living with disabilities worldwide is between 93 and 150 million. The 2007 EFA Global Monitoring Report estimated that one third of the 77 million children out of school have disabilities and that less than 10 percent of children with disabilities in Africa attend school (United Nations Educational, Scientific, and Cultural Organization (UNESCO), 2007). Some research does suggest that children with disabilities are more likely to drop out, never attend school or participate in a parallel set of schools designed specifically for them (Croft, 2010; WHO, 2011). In addition, the WHO (2011) found that, “This pattern [towards inaccessible education] is more pronounced in poorer countries” (p. 206). Children with disabilities are the most marginalized in the world, routinely denied access to basic rights, like education.

Filmer’s (2008) analysis of 14 country household surveys found that children with disabilities are much less likely to attend school and “less likely to acquire the human capital that will allow them to earn higher wages” (p. 159). In a 51-country analysis, the

WHO (2011) discovered that there was approximately a 10 percent difference in completion of primary school in males and females with and without a disability, students with disabilities being the lower of the two groups (p. 206). When this is broken down by country, the numbers are drastically different. Filmer (2008) found,

The gap in primary school attendance rates between disabled and non-disabled children ranges from 10% in India to 60% in Indonesia...Household data in Malawi, Namibia, Zambia, and Zimbabwe shows that between 9% and 18% of children age 5 years or older without a disability had never attended school, but 24% and 39% of children with a disability had never attended. (p. 206-207)

These data show the need for improvement in all aspects of education, but especially for those with disabilities. For a student with regular cognitive function, but perhaps a visual or hearing impairment, the exclusion from school places a burden on the family because that child has an earning potential. Jonsson and Wiman (2001) cited a World Bank study which found that when people with disabilities were included in the classroom, there were economic benefits such as reduction in social welfare costs and dependence on the state, increased productivity, overall improvement in quality of life, etc. Although the study did not specify, it is logical to assume that these were people with mild to moderate disabilities. The numbers from the WHO (2011) 51-country survey show that some children with disabilities are attending school, but what is the quality of their education? In her background paper for the 2010 EFA Monitoring Report on Rwanda and Ethiopia, Lewis (2009) asserted, “Those disabled learners who are enrolled in a mainstream school may still be marginalized – not participating or achieving” (p. 19). Even though some

children with disabilities attend school, there is a likely chance that they are not actually accessing an education.

Education is universally understood to be a path out of poverty and that access to education is needed to develop the human and social capital to gain permanent employment, thus increasing one's quality of life. The WHO (2011) pointed out that, "For children with disabilities, as for all children, education is vital in itself but also instrumental for participating in employment and other areas of social activity" (p. 205). This connection between education, employment and social activity can be seen in the QOL index discussed in the next chapter. In addition, the WHO (2011) makes the case for destigmatization through inclusion by stating, "For children who are not disabled, contact with children with disabilities, over the long term, increases familiarity and reduces prejudice. Inclusive education is thus central in promoting inclusive, equitable societies" (p. 206), which could lead to a higher QOL. The authors of the WHO (2011) study make a clear connection between the livelihoods of people with disabilities and the need to create an inclusive education environment. They stated, "A lack of education at an early age has a significant impact on poverty in adulthood. In Bangladesh the cost of disability due to forgone income from a lack of schooling and employment, both of people with disabilities and their caregivers, is estimated at US\$ 1.2 billion annually" (WHO, 2011, p. 208). As this study suggests and as the next section will support, people with disabilities are able to make economic contributions to society when given the proper tools, such as increased social and human capital, through education and societal inclusiveness.

### **Economics of Disability**



Disability costs more. It is that simple. There are more medical bills, more forgone income, higher architectural cost to building due to ramps, elevators, etc. This leaves many people with disabilities further in poverty because they need more to reach the same social level as someone without a disability, even in more developed countries (see Kuklys, 2005). Sen (2009) pointed out, “the disabled are quite often the poorest of the poor in terms of income, but in addition their *need* for income is greater than that of able-bodied people...” (p. 258). Sen (2009) coined the terms *the earning handicap*, to refer to the difficulty in retaining employment, and *the conversion handicap*, which is, “the difficulty in converting incomes and resources into good living, precisely because of disability” (p. 258). Mont and Viet Cuong (2011) examined this idea in Vietnam where the poverty rate is 15.09 percent for the general population, while the poverty rate for people with a disability was 17.16 percent. They found that when adjusted for the extra expenditures needed due to a disability, the poverty rate jumped to 22.31 percent. Research from both more economically developed countries, such as Kuklys (2005) in the United Kingdom, and less economically developed countries, such as Mont and Viet Cuong (2011) in Vietnam, have found that poverty affects people with disability more disproportionately than people without disabilities. Unfortunately, poverty alleviation programs in many countries do not take into account the extra needs of people with disabilities and for the most part, fail to include these needs in the development process, as my research will show, in terms of educational inclusion, and as Mitra *et al.*, (2013) pointed out on a more global/national scale.

### **Successful Programs in Helping People with Disability**

When looking at the broad picture of disability worldwide, one can get lost in the marginalization and ignorance. However, it is important to remember that there are success stories. Swartz, Schneider and Rohleder (2006) pointed out the disability grant offered by the South African government has helped many families survive financially in a country with high unemployment. Unfortunately, the policy of distribution is not uniform throughout the country. Though Ghana, Bangladesh and Zambia also use disability allowances, the allowances are not without controversy. In a study conducted by Marriott and Gooding (2007), a Zambian respondent “felt that support for a disability allowance is counter to the government’s argument that it is looking at social inclusion and empowerment” (p. 13). Others in the same study on Zambia felt that the assistance helped people rise out of poverty, empowering them and giving children a chance to attend school, whereas, before this, they had been forced to stay home with a disabled parent.

In education, many countries are developing pilot programs with some success. In Ethiopia, Lewis (2009), found a program where students with intellectual disabilities were admitted to schools through a pilot program on inclusion, and 16 teachers received a month-long training on adapting their teaching methods. In addition, parents, Education Bureau personnel, teachers, and children participated in a one-day workshop that raised awareness on inclusion and children’s rights. After a year, “the project found a significant increase in teachers’ willingness to teach children with intellectual impairments in their regular classes” (Lewis, 2009, p. 33). In Lesotho, Johnstone and Chapman (2009) discovered that teacher attitudes positively changed towards students with disabilities in 10 pilot schools, which they attribute to the national policy. Unfortunately, they also

found that most of the teaching practices stayed the same and suggested that more intervention might be needed. One success that can be seen in Mexico (see Fletcher & Artiles, 2009), South Africa (see Naiker, 2009), Qatar, Bahrain and Kuwait (Brown, 2009) is the development of inclusive education policy. The difficulty comes in turning that policy into action. Brown (2009) stated, “The disparity between rhetoric and reality in implementing the public policy on inclusion is great” (p. 276) when discussing Qatar, Bahrain and Kuwait. Putting great ideas into the policy in all these countries has had great success, but the next and possibly most difficult step is to turn those policies into a reality for children.

Disability is much more than a percentage of the population or the difficulties associated with life with disabilities. Behind each research finding is person who desires access to basic services. The successes illustrated above show the achievements that can be obtained by implementation of inclusive policy and understanding of the lives of people with disabilities. The way to finding inclusiveness on a national level and understanding the lived experiences of people with disabilities is key to creating an environment and society that is welcoming and accommodating to difference.

### **Theories on Disability**

There are two ways researchers examine the life of a person experiencing a disability. One way is from the medical perspective. This medical model looks at disability from a purely medical perspective (International Classification of Functioning, Disability and Health (ICF), 2002). Another way is the social model, which examines disability as a social construct (Barren & Amerena, 2007; Devlin & Pothier, 2006; Kahane & Savulescu, 2009; Siebers, 2008; WHO, 2011). In the early stages of the

disability movement, many people focused on changing the medical model. The medical model focused on fixing people with disabilities. Many people with disabilities were institutionalized and experienced complete segregation from society (Campbell & Oliver, 1996). Today, the focus has shifted to rights-based campaigns, which have helped to create the Salamanca Agreement and the UNCRPD.

### **Critical Disability Theory**

The disability movement has evolved over the last century from a medical based *curative* model to a social based *human rights* model. Critical disability theory developed out of the human rights model and helps researchers to explain the *why* in terms of social exclusion and ignorance towards the plight of people with disabilities as a socially constructed second-class citizen. “A critical disability theory approach offers an important lens in unraveling the inherent complexities associated with disablement and equality” (Rioux & Valentine, 2006, p. 47). Critical disability theory explains why these children are forced to attend an exclusive school and why children without disabilities and their parents are hesitant to send their children to the Center, even though the director of the Center stated that he would welcome any child, not just those with disabilities (personal communication, 6 December 2012).

The social model of disability is a newer model that grew out of the disability rights movement and views disability as more of a social construct, rather than from the individual, medical perspective. The social model furthered theoretical discussion on disability and society, which led to the development of critical theory on disability. According to the social model, disability is more of a human rights issue than a medical issue. It is not a person with a disability that needs to conform, but society that must be

flexible (Barren & Amerena, 2007; Kahane & Savulescu, 2009; WHO, 2011). Croft (2010) argued that, “Disability is...increasingly being recognized as a social construct in a similar vein to gender, ethnicity and sexuality” (p. 4). Kahane and Savulescu (2009) extended that idea: “[disability] makes [life] worse in the same way that dark skin...can make life worse in a racist society” (p. 22). The focus of this model is on the environment and the ways in which that setting can be more enabling (or disabling) for an individual with a disability. Barren and Amerena (2007) pointed out that, “The focus is on assessing the environment not only the impairment to identify what interventions need to be made in the environment to enable the individual to participate in society as fully as other people” (p. 10). The social model places the responsibility on the society and government to shift thinking and actions to create an inclusive society.

Although the social model is the current trend in theories on disability and rights, the medical model is still a part of societies around the world. The medical model focuses on disability as a part of the person; something that needs to be treated or corrected by medical professionals (WHO, 2002). We can see it in the language we use to describe disability. *He is autistic. She is developmentally delayed. He is mentally retarded. She is deaf. He is a person with a disability.* These phrases and association come out of the medical model of looking at a person *as* their disability. The language “categorizes the individual to conditions and symptoms...” (Barron and Amerena, 2007, p. 9). Pothier and Devlin (2006) point out that, “we do not speak of ‘persons with a gender’ or ‘persons with a race’” (p. 4). Unfortunately, this language has led to the formation of a sub-human category of *a person with a disability* or *a disabled person*, which creates a stigma and decreased QOL (Barron and Amerena, 2007, p. 9). It is not to say that the medical model

has not developed helpful and useful aids for a person with an impairment. Barron and Amerena (2007) assert, “Few would question what nurses, doctors and other medical specialists deliver is of tremendous importance, as they strive to address physical, sensory and mental impairments” (p. 9). However, they qualified that with, “The medical model... [focuses] on the impairment and not the person and certainly not on the society in which the disabled person lives” (p. 9). The medical model is very useful in some situations, for example, when developing medical policy or offering medical services in a community (McColl, James, Boyce, & Shortt, 2006). However, this model is outdated when referring to the needs of a person with an impairment in a societal context.

Critical disability theory expands the social model to take a more serious look, questioning the very citizenship of people with disabilities to not only a country, but also the human race. Critical Theory came out of the Frankfurt school in Germany during the rise of fascism and Nazism, when any person slightly different in faith, physical ability or appearance from the *ideal* German was not considered human enough to be in the local population, and so for millions that meant death. The Nazis wanted to form the ideal Aryan race and eliminate any person who did not adhere to that description. In opposition to the White supremacy ideology, Critical Theory seeks, “human emancipation” in circumstances of domination and oppression” (Bohman, 2005). As shown in earlier sections, people with disabilities are often considered a small, irrelevant group that are not able to contribute to the economic stability of a country, even though recent research presents a different reality (see Buckup, 2009; Braithwaite *et al.*, 2008). The stigma is so strong that many participants in my study recalled stories of children being abandoned or

dumped at boarding schools. This type of marginalization requires a critical lens to fully understand the lives of the children at the Center.

Critical disability theory is a critical social theory that questions society's exclusion of people with disabilities by encouraging, "the production and application of theory as part of the overall search for transformative knowledge" (Leonardo, 2004, p. 11). In a search for this transformative knowledge, Devlin and Pothier (2006) suggested four central themes for critical disability theory: (1) language, definition, and voice, (2) contextual politics and the politics of responsibility and accountability, (3) philosophical challenges and (4) citizenship/dis-citizenship. These four categories aid in the exploration of discovering transformative information that may help readers and participants understand the true marginalization these children face and better ways to create an inclusive society.

**Language, definition, and voice**—The very language used to describe people with disabilities automatically sets them apart from the rest of society. The current descriptor used for disability is known as person-first language, as in, a person with blindness or a person with autism. It replaces other terms such, "the crippled," "the handicapped," "the retarded," etc. However, Tichkosky (2001) suggested, "...the assumption that people-first phraseology is devoid of objectification, and is simply appropriate and non-hurtful, 'dams' the possibility of critical analysis of this unified discursive formulation of disability..." (p. 128). This language still sets people with disabilities apart from people without disabilities in common conversation. They are *people with something*, a caveat to show that they are different. Devlin and Pothier (2006) pointed out that this does not happen with other differences, such as gender or race.

Titchkosky (2001) makes the argument that person-first language still focuses on the limitation, and the author stated: “Bodies differ, sense-abilities differ, minds differ. *All* people possess these differences, but only some of these differences have been defined in terms of lack and limitation” (p. 133). In a counter argument to Titchkosky (2001), Devlin and Pothier (2006) pointed out that in terms of sociology, Titchkosky’s critiques are very important; however, in laws, the idea of personhood is significant. The authors refer to the United States Constitution that counted slaves as only three-fifths of a person.

Another example might be the current debate on same-sex marriage. The authors pointed out, “To be a person is to have the capacity to appear on the political radar” ( Devlin & Pothier, p. 3). This is a step up from the non-person language, such as “retarded” or “handicapped.” The discussion on the use of language is difficult. In some instances, such as research, there is a need to separate those with a disability and those without, or in a law to create an equal playing field and inclusive society. The problem arises in society when the terms are used all the time, in every conversation, to separate those with differences and those that are without.

The definition of disability is a discussion in political discourse. Devlin and Pothier (2006) stated, “...there is no apolitical way to think or talk about either impairment or disability, because language itself is an unavoidable political phenomenon” (p. 7). I have chosen to use the universally accepted WHO definition, but this definition does not come without its critiques. Although it encompasses many different limitations and is widely used, it still has what we, as a society, have historically tended to adopt in a definition of disability, which is a “binary conception of disability...the disabled (them-us) and the able-bodied (us-them)” (Devlin & Pothier,



2006, p. 5). Critical disability theory does not advocate one definition over another. It does not state that person-first language is better than other language, but wishes to develop a conversation on the categories societies create in terms of *othering* a group of people (Devlin & Pothier, 2006). In this research, I am looking at a specific set of severe disabilities and how children with those disabilities have been affected because of the definition society forces upon them; i.e., in Liberia people with disabilities are defined as witches or demons, or less than human or *bobo*. This conversation of language is an important step in developing transformative knowledge about disability and society.

The rallying cry of the disabilities movement is *nothing about us, without us*. This means that people with disabilities must be given the power to determine their futures. Many people call for the advancement and equalization of rights for people with disabilities, but unless people with disabilities are given a voice in the discussion, the norm of the disabled vs. the able-bodied is perpetuated. For the purposes of critical disability research, I must point out that I do not identify as a person with a disability and therefore must be aware of my use of others' experiences to explain the lives of these students. I have attempted to give a voice to the voiceless by providing in-depth profiles that encourage the reader's analysis of the situation before providing my analysis of the research.

For children with disabilities, especially for those with communication differences, the voice of the parent is of particular importance. With disability, the question of marginalization extends to those without disabilities, such as parents, caregivers and sometimes friends or other family members, making the question of the

disability experience very complex, something that may not happen with other critical spectrums. Siebers (2008) suggested,

...that it may be argued that women alone understand feminine experience, or African Americans, black experience, and that only they should be allowed to represent the political concerns of their respective groups, but activists struggle both to represent the experience of disability in general and the experience of different disabilities in particular. The question confronting the disability community is not only how to design a unified political coalition among people with different impairments but how to determine when a blind person, for example, may represent a deaf person in a political debate. (p. 188)

Siebers' (2008) question can be extended to the use of the parental voice in studies on education and disabilities. In studies where the focal point is on a child with a severe disability that manifests as a communication difference, I would argue that the parent could act as a communicator for the child. There are validation issues that will be discussed later. For research on children, the family has a close connection. Baker (2006) pointed out, "...the family as the holder of the child's rights is not unique to children with disabilities. However, the role that must be played in the exercise of those rights is...more demanding for the parents of children with disabilities" (p. 184). Indeed, education and disability rights movements across the world have begun with a parent demanding equal opportunities for their children.

#### **Contextual politics and the politics of responsibility and accountability—**

Critical disability theory is not a theory merely for the sake of theorizing. It is "theorization in the pursuit of empowerment and substantive, not just formal, equality"

(Devlin & Pothier, 2006, p. 8). It suggests that, “issues of disability are not just questions of impairment, functional limitations, or enfeeblement; they are issues of social values, institutional priorities and political will. They are questions of power: of who and what gets valued, and who and what gets marginalized” (Devlin & Pothier, 2006, p. 9). The issue of power is discussed in many different critical theories; in critical disability theory, the idea of power manifests itself in terms of substantive equality. Inherent in substantive equality is the notion that everyone is different with different needs. This may seem to go against the very tenets of critical disability theory not to focus on *otherness*, but this discussion is meant to identify the inequalities in order to change the power structure and give people with disabilities a powerful voice, rather than a muted one. Devlin and Pothier (2006) provide this example,

Substantive equality necessitates taking difference into account in order to both identify the systematic nature of inequality and pursue solutions tailored to the goals of full inclusion and participation. This is even more crucial in the context of disability than elsewhere because to ignore the difference of disability is to engender exclusion. If the sign says that all are welcome, then gender or race is not an absolute barrier to getting in the door, but a set of stairs is an absolute barrier for a wheelchair user. (p. 12)

Substantive equality considers the differences without placing the blame of disability on the person with a disability. It places the responsibility to create an equal society on society (Devlin & Pothier, 2006, p. 12). The responsibility of creating an equal society must be placed in the hands of both the disabled and non-disabled, especially when the power structure tends to give power to the able-bodied. People with disabilities must

accept that they have the power to overcome the oppression that surrounds them. In *Pedagogy of the Oppressed: 30<sup>th</sup> Anniversary Edition*, Paulo Freire (2009) stated, “In order for the oppressed to be able to wage the struggle for liberation, they must perceive the reality of oppression not as a closed world from which there is no exit, but as a limiting situation which they can transform” (p. 49). Just as the able-bodied must understand and embrace people with disabilities, people with disabilities will manifest the change they want. In Liberia, as will be shown, this is an issue. Those with disabilities do not appear to see themselves as people that are able to transform, but as people that are in need of the help of the able-bodied. Freire (2009) places more emphasis on the oppressed gaining freedom through reflection and praxis; however, for critical disability theory the responsibility must be shared. Substantive equality will not be achieved until the needs of the powerless (the disabled) are effectively voiced to the powerful (the able-bodied) and the oppressed are taught to voice their needs.

**Philosophical challenges**—Critical disability theory sees disability as a social construct. Everyone has differences, but society places a hierarchy on difference. Devlin and Pothier (2006) pointed out, “Persons with disabilities may experience functional limitations that non-disabled persons do not experience, but the biggest challenge comes from mainstream society’s unwillingness to adapt, transform, and even abandon its ‘normal’ way of doing things” (p. 13). A shift in philosophical thinking about what is disability and society’s approach to moving past difference is a key component to the tenets of critical disability theory.

All societies have a presumption of normalcy, or what I will refer to as the *normalcy bar*, which helps a person within that society gauge whether someone is *normal*

or *abnormal* based on preconceived notions placed on people in a given society. For people with disabilities, there is a presumption of normalcy or a presumption that people with disabilities must attempt to fit into the idea of *normal* for a given culture. Devlin and Pothier (2006) stated, “A person with a disability may try to blend in as much as possible, trying to downplay the significance of the disability. This is a process of accommodating oneself to one’s environment, while asking...little to no effort of the environment...” (p. 16). Foregoing the idea of *normal* person gives rise to the idea that all people are just human. We, as a society, can begin to seriously create an inclusive society that looks past disability and more at the abilities of various people.

**Citizenship/dis-citizenship**—Citizenship is not just an association with a country, as for example, *I am a citizen of the United States*. Nor is it just the ability to hold a passport. It is at the very heart of societal acceptance as a human being, a concept that people with disabilities are often denied through systematic exclusion, creating a second-class *dis-citizen*. Devlin and Pothier (2006) pointed out

...the substantive approach [to citizenship] raises questions of access and participation, exclusion and inclusion, rights and obligation, legitimate governance and democracy, liberty and equality, public and private, marginalization and belonging, social recognition and redistribution of resources, structure and agency, identity and personhood, and self and other. (p. 2)

Critical disability theory uses the idea of *dis-citizenship* to create new ways to conceptualize the idea of disability, not as a question of medical or health, but as a political question of power. Rioux and Valentine (2006) suggested this about critical disability theory,

It begins with the assumption that theories of human rights and equality provide the necessary foundation for understanding the linkages between the existing legal, economic, political, and social rationales for the full inclusion of people with disabilities, and the systematic barriers and oppression that continue to construct people with disabilities as inherently unequal and disentitled to citizenship rights. (p. 47-48)

Citizenship is connected to the argument of slavery in an earlier section. Slaves were denied citizenship because they were property of another person and were therefore less than human, on the same ranks as animals that can be bought and sold. This extreme example can be connected to the mental connection to being a true citizen of a nation, being about to participate in a country's national narrative. Unfortunately, people with disabilities are often denied that right because of exclusionary practices. It also brings into question the very idea of citizenship and what it means to be a *citizen*. Rioux and Valentine (2006) pointed out, "...citizenship is a messy concept, and therefore its boundaries are often contested. It constructs a system of inclusion and exclusion, defining boundaries between who belongs and who does not, who enjoys privileges...associated with membership and who is denied..." (p. 54-55). People with disabilities are denied access to certain parts of society in every country because society sees them as somehow less. If they do succeed, they are added to the list of "people with disabilities that are famous," again associating the person with a disability, rather than just a person.

In conclusion, critical disability theory looks at philosophical questions of *humanness* in a population that is often considered *sub-human*. Critical disability theory's four areas of focus have one major theme: power. The issue of power is at the heart of

political and theoretical discussion on disability. Who has the power to create a definition of disability? Who has a voice in society? Who is considered an active, valuable member of society? The answer is not people with disabilities in Liberia for each of these questions. The answer for each of these questions, unfortunately, is not people with disabilities in Liberia.

### **Quality of Life Research**

Quality of Life (QOL) researchers study an individual's quality of life compared to a country's or global quality of life. QOL researchers use social indicators, such as poverty rates, school attendance, life expectancy or gross domestic product to subjective well-being assessments. Rapley (2003) stated,

...when talking about QOL, the literatures invoke matters ranging from objective estimations of the life circumstances of individuals, to those individuals' 'subjective' estimations of their appreciation of those circumstances; from macroeconomic indicators, the 'amounts' of other abstract quanta such as 'human' and 'social capital' ...such economies 'possess', to individual happiness with material circumstances. (27)

QOL research's broad range lends itself to a variety of different research questions and goals.

### **Social Indicators**

Social indicators are very important to help create the context from which one builds one's feelings or measures one's QOL. Amartya Sen's (1999) capabilities approach complements subjective quality of life research, by placing emphasis on the

objective<sup>3</sup> nature of quality of life. The following section will review Sen's capabilities approach; in further sections and chapters, this objective data will be used to analyze the context of the subjective state of being of the participants in the study.

In the 1980s, Amartya Sen developed the "capabilities approach" that looks outside traditional economic indicators to discuss development. In his book, *Development as Freedom* (1999), he stated,

An adequate conception of development must go much beyond the accumulation of wealth and the growth of gross national product and other income-related variables... Development has to be more concerned with enhancing the lives we lead and the freedoms we enjoy. (p. 14)

His approach to development focuses on the freedoms, for example, political, social and economic freedoms to increase the quality of life of individuals as a means to economic development. Economic development becomes one part of the development process and not the ultimate ends. Sen (1999) refers to the need for development to remove sources of *unfreedoms* such as, "poverty...tyranny, poor economic opportunities...social deprivation, neglect of public facilities [and] intolerance" (p. 3). Sen (1999) sees freedom as the ultimate means and ends to development.

Sen (1999) refers to many freedoms as substantive freedom, which is the ability, "to choose a life one has reason to value" (p. 74). Sen (1999) defines this ability in terms of functionings and capabilities. Capabilities and functionings are the foundation of Sen's approach to development. Functionings are "various things a person may value doing or

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<sup>3</sup> It should be noted that data is rarely purely objective. Most data can be manipulated or skewed to fit an idea or outlook.



being” (Sen, 1999, p. 75). Sen (1999) pointed out that these can be in terms of nourishment and health or “being able to take part in a life of community and having self-respect....Capability is...the substantive freedom to achieve alternative functioning combinations (or...the freedom to achieve various lifestyles)” (p. 75). Sen gave a good example of a wealthy man fasting and poor man starving; both are functioning at the same level, but the “first [wealthy] person [has] a different ‘capability set’ than the second (the first can choose to eat well...in a way the second cannot)” (p. 75). This research uses the capabilities of Liberians and compares them to the families’ access (or lack thereof) to various parts of Liberian society as a way to discuss the influence the Center might have on the quality of life of the students.

### **Subjective Well-Being Theory**

Objective and subjective data measures are useful to create a holistic picture of the life of an individual (Diener & Suh, 1997). When a researcher only uses subjective data, it gives a skewed version of reality, yet, it is the reality of the participant. Deneulin and McGregor (2010) pointed out, “that a person may feel happy or be subjectively satisfied as result of the psychological adaptation which is necessary to cope with their dire life circumstances” (p. 506). For example, when looking at policy needs of a community, asking if one is happy is relative to the person’s psychological state, not necessarily one’s needs. One can be happy and not have access to clean water, but having access to clean water would greatly improve the individual’s quality of life. Only using

objective data will not give the whole picture. Diener and Suh (1997) give the example of underreported rape. Simply because a rape is not reported does not mean it did not happen; but if only objective measures are used, it might seem as though rapes do not occur (p. 195). Disability is another example. As noted earlier, many Liberians do not report a child with a disability because of stigma. This does not mean that there is no disability in Liberia.

At the micro level, subjective well-being theory is the basis for much quality of life research. Diener (1994) stated that subjective well-being theory is the idea that humans are not only capable of appraising events, life circumstances, and themselves, but they make such appraisals continually. An appraisal of things in terms of goodness-badness is a human universal. According to Diener (1994), there are two levels of subjective well-being: life satisfaction and hedonic level. Life satisfaction refers to work, love, etc. and hedonic level refers to, “the pleasantness minus unpleasantness of one’s emotional life” (p. 108). These two categories can be broken down into different domains to explain further collected data, such as the different domains for the QOL framework presented later in this chapter. Subjective well-being theory gives a background to the ideas behind the dimensions and domains in Schalock and Keith’s (2000) Quality of Life framework.

Schalock and Keith’s (2000) framework encompasses the micro, meso and macro systems of a person’s life. Keith and Schalock (2000) cited Bronfenbrenner’s (1979) concept of ecological systems when defining micro, meso and macro systems.

1. *Microsystem*: the immediate social setting, including person, family, and/or advocate

2. *Mesosystem*: the neighborhood, community, or organizations providing education or habilitation services or supports
3. *Marcosystem*: the overarching patterns of culture, society, larger populations, country or sociopolitical influences. (p. xvi)

By using Schalock and Keith's (2000) eight domains—emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights as a guiding framework—I will incorporate the micro, meso, and macro systems into my research. This section will review the history of QOL, give an overview of the framework and connect it to the Center's objectives.

### **What is a Quality Life?**

How do I determine if I have a good quality of life? The question has been in existence since the beginning of human thought. Diener and Suh (1997) point out that in "Aristotle's concept of *eudaimonia*, individuals were called on to realize their full potentialities in order to achieve 'a good life'" (p. 190). Phillips (2006) pointed out, "Most of us have a reasonably clear idea of what sorts of things would enhance our individual quality of life..." (p. 2). For some, money enhances their quality of life; for others, freedom of choice is important; and for others, power increases their quality of life. There are some basic principles that are universal to increasing one's quality of life. Phillips (2006) suggested that even on a global scale, people can agree that, "a peaceful, non-coercive and congenial social environment; social norms of interpersonal respect; a sustainable and pollution free-environment...provision of education...adequate physical, economic and nutritional resources" (p. 1) would be good for everyone. This is true, but

each of those ideas is value-laden and people have different definitions for what constitutes *adequate* or *peaceful*, for example. This is where the idea of quality of life becomes difficult, almost impossible to define for researchers, and is the topic of many, many books, articles, and studies (Rapley, 2003). The history of QOL research is a good place to begin to discuss the framework used in this research.

The history of quality of life and social indicators, as we see it today, gained momentum as a political concept in the 1960s and 1970s. In the beginning, QOL was tied to the idea of material wealth, national indicators of GNP, progress, and used for political means to understand the measure of society's achievements. It was further theorized by writers in Scandinavia and the United States into two very different definitions, which separated the QOL indicators into two categories, objective and subjective, respectively (Rapley, 2003). The Scandinavian researchers thought resources were needed to obtain a good quality of life. Resources were defined in the objective manner, "of money, property, knowledge, psychic and physical energy, social relations, security, and so on" (Rapley, 2003, p. 5). American researcher's QOL assessment was based at the individual level in measures of satisfaction and happiness, very subjective terms (Rapley, 2003). In the 1960s, the social indicator movement gained momentum in the U.S. with the joint efforts of National Aeronautics and Space Administration (NASA) and the American Academy of Arts and Sciences (AAAS). NASA and AAAS were commissioned to "predict the societal effects of the space race" (Rapley, 2003, p. 5). Social indicators were defined by the head of the project as, "statistics, statistical series, and all other forms of evidence that enable us to access where we stand and are going with respect to our values and goals" (Noll (2000) as cited by Rapley, 2003, p. 5). This project was not an isolated

event. Land (2004) points to the Johnson Administration's 1969 document, *Toward a Social Report* and Angus Campbell, Phillip E. Converse, and Willard L. Rodgers' book, *The Quality of American Life: Perceptions, Evaluations, and Satisfaction* as being influential in developing the social indicators that evolved into the QOL indicators of today. In addition, the increased prosperity coupled with the socially and politically volatile climate of the 1960s and 70s created an atmosphere that questioned economic growth "as the major goal of public policy" (Rapley, 2003, p. 6), giving rise to social progress as a primary indicator. This has been seen more recently again with the anti-globalization movements (Rapley, 2003).

The term *quality of life* became ubiquitous in the 1980s and 90s with the rise of neo-liberal politics, beginning with the Thatcher and Reagan administrations. In an interview with Community Living British Columbia, Robert Schalock points out that the terms surrounding QOL "quickly became a sensitizing language" (Community Living BC, 2011). Neo-liberal ideology focused more on the individual and with that, QOL followed suit. "In this environment, the notion that quality of life was a property of individual persons became an 'idea whose time had come'" (Hatton, 1995, p. 25 as cited in Rapley, 2003, p. 8). This leads to the issues of QOL research today.

Today, many different QOL indices are used across disciplines and sectors. A few objective measures are: The WHO (n.d.) Quality of Life-BREF, the Center for Disease Prevention's (n.d.) Health-Related Quality of Life, and the Economist Intelligence Unit's quality of life index (2005), the UNDP's Human Development Index, and the OECD's (n.d) Better Life Index. The sheer number of different indices can be a problem as Rapley (2003) cautioned,

QOL has become an increasingly slippery or complex construct over the course of its use. It is now widely used to describe everything from the state of nations' bank balances to the happiness of individuals with the contents of theirs. QOL describes outcomes of political projects, as well as how pleasant (or otherwise) it is to live in Brisbane, Berlin, or Beijing. QOL describes the judgments of individuals about their happiness with their sexual relationships, club membership and domestic arrangements, and what will be exponentially improved...by the purchase of this or that washing powder, package holiday, or new home. QOL simultaneously indexes the levels of crime, home ownership, and participation of women in government in the nation state, and signifies the 'output' of unconscious brain states. (p. 10)

All of these indices can make it difficult for research to determine the most appropriate framework to use. I have chosen Schalock and Keith (2000) for its validity and reliability, which will be discussed in a subsequent section.

### **Definition of QOL**

There are many different definitions to QOL. Chung, Cheung, Killingworth, and Nolan (1997) points out, "that at least 800 possible dimensions of quality of life have been identified..." (p. 81). There is no clear consensus on quality of life and Rapley (2003) argues that it comes down to the researcher's choice (p. 61). Since I will be using Schalock and Keith's (2000) framework, I will use their definition. "In reference to the meaning of the term *quality of life*, 'quality' makes us think about the excellence associated with human values, such as happiness, success, wealth, and satisfaction, whereas 'of life' indicates that the concept concerns the very essence or essential aspects

of human existence” (Schalock *et al.*, 2002, p. 458). There are three basic assumptions to this definition when conducting research with individuals with intellectual disabilities:

Quality of life is:

1. [a] sensitizing notion that gives us a sense of reference and guidance from the individual’s perspective, focusing on the person and the individual’s environment.
2. [a] social construct that is being used as an overriding principle to enhance an individual’s well-being and to collaborate for change at the societal level; and
3. [a] unifying theme that is providing a common language and a systematic framework to apply quality of life concepts and principles. (Schalock *et al.*, 2002, p. 458).

Vergugo *et al.* (2005) added characterizations to the Quality of Life framework. They stated:

(1) Its multidimensional nature involving core domains and indicators; (2) the use of methodological pluralism that includes the use of subjective and objective measures; (3) the use of multivariate research design to evaluate the ways that personal characteristics and environmental variables relate to the person’s assessed QOL; (4) the incorporation of systems perspective that capture the micro, meso, and macro levels; and (5) the increasing involvement of persons with intellectual disabilities in the design and implementation of QOL-orientated assessments, research and evaluation. (p. 707)

In this sense, some QOL research has been emancipatory in nature. Although this research is not emancipatory in design, there are hopes that it will aid in policy development and will have possible emancipatory effects later. The participants in my study are not included in the research design and I do not foresee any dramatic change in the students' attitudes towards themselves or others. However, the participants in the study will have an impact on the outcome of the study and could add or remove elements based on the QOL framework presented. Oliver (1997) reflected on his almost 20-year career with this, "After much critical reflection on my own work...during the 1980's, provoked by my involvement in the disability movement, I came to the inescapable and painful conclusion that the person who had benefited most from my research on disabled people's lives was undoubtedly me." I understand that I am the one most benefiting from the Center letting me enter their space and conduct this study. It is my hope that this could have an impact on policy, but again, I steer away from calling it emancipatory, because I do not want to misrepresent the research.

There are problems with this definition and Rapley (2003) argues that the values listed are associated with the "American Dream", not a worldwide concept. Rapley (2003) criticizes the definition by stating, "...to claim that 'values such as happiness, success, wealth, health, and satisfaction' are universally 'positive' is simply to be blinded by ethnocentrism" (p. 52). However, I see those values as suggestions of the authors, not concrete *must-haves*. Those values will change in Liberia and I see the framework as being open to changing with those values.

**Schalock and Keith's (2000) Quality of Life index**



I have chosen to use Schalock and Keith's (2000) conceptual model of the QOL listed in Table 1 below. Rapley (2003) states that this framework "recognizes the multifactorial nature of the construct, its individually specific, yet culturally homogeneous, domains of reference; and acknowledges that the experience of intellectual disability is essential to QOL judgments and, further, recognizes the interactive—indeed socially constructed—nature of the concept" (p. 169). It has been cross-culturally tested (Keith & Schalock, 2000) and Barron and Amerana (2007) state that it "may be particularly helpful in assessing the needs of families looking after a disabled relative" (p. 25). For this research, I see it as helpful in identifying some basic domains from which to assess the impact the Center has on the quality of life of the students and their families.

**Table 1: Quality of Life Index Indicators**

Dimension	Indicators	
Emotional well-being	Safety Spirituality Happiness	Freedom from stress Self-concept Contentment
Inter-personal relations	Intimacy Affection Family	Interactions Friendships Supports
Material well-being	Ownership Financial Security Food	Employment Possessions Socio-Economic Status Shelter
Personal Development	Education Skills Fulfillment	Personal competence Purposeful activity Advancement
Physical well-being	Health Nutrition Recreation Mobility	Health care Health insurance Leisure Activities of daily living
Self-determination	Autonomy Choices	Personal Control Self-direction

	Decisions	Personal goals and values
Social Inclusion	Acceptance Status Supports Work	Community activities Roles Volunteer activities Residential environment
Rights	Privacy Voting Access	Due Process Ownership Civic responsibility

Source: Schalock and Keith (2000)

By analyzing the QOL framework and the Center's objectives, I have developed a table that connecting the two, as Table 2 shows.

**Table 2: Quality of Life Index - the Center's Objectives**

Dimension	The Center' Objectives
Emotional well-being	<ul style="list-style-type: none"> <li>• Performing regular visits to gain a sense of how the student is treated in his or her home environment</li> <li>• Counsel the families on how to treat the child correctly and include him or her in family activities</li> <li>• Provide support for families who are struggling under the stress or perceived burden of caring for a child with special needs</li> </ul>
Inter-personal relations	<ul style="list-style-type: none"> <li>• To stimulate children with disabilities and develop their social skills in contact with other children</li> </ul>
Material well-being	
Personal Development	<ul style="list-style-type: none"> <li>• To give to children with disabilities the opportunity to learn how to be independent in the activities of daily life</li> <li>• To educate children with disabilities with the help of special instructors</li> <li>• To include the families in the goal setting and assessment process for each student</li> </ul>

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Physical well-being	<ul style="list-style-type: none"> <li>• Performing regular visits to gain a sense of how the student is treated in his or her home environment</li> <li>• Counsel the families on how to treat the child correctly and include him or her in family activities</li> <li>• Provide support for families who are struggling under the stress or perceived burden of caring for a child with special needs</li> </ul>
Self-determination	<ul style="list-style-type: none"> <li>• To stimulate children with disabilities and develop their social skills in contact with other children</li> </ul>
Social Inclusion	<ul style="list-style-type: none"> <li>• Educate families and communities on appropriate treatment of people living with disabilities in order to address the issues of isolation and stigmatization</li> </ul>
Rights	<ul style="list-style-type: none"> <li>• Advocate for the inclusion of children with disabilities throughout Liberia</li> </ul>

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Material well-being was the only objective I was unable to connect to the Center's objectives; however, the need for basic material well-being did arise in the conversations with participants.

This framework provides a good basis from which to study the QOL on students with disabilities. It provides distinct domains, but has the ability to change and adapt to the needs of the community. In addition, it connects all levels of a person's life: micro, meso and macro. This is very important when studying students with disabilities because of the need many of them have for support. Other models, such as the WHO (1997), with domains of physical health, psychological, level of independence, social relationships, environment and spirituality/religion/personal beliefs, does not include social inclusion, rights or emotional health. These three domains are very important to people with disabilities because of their exclusion from mainstream society on a regular basis, and being denied basic rights, like education, which would affect anyone's emotional well-

being. The final reason I have chosen this framework over others is that it has been employed and proven useful when researching people with disabilities (Rapley, 2003; Schalock *et al.*, 2002; Verdugo *et al.*, 2005).

### **Chapter Summary**

This chapter examined the literature associated with global disability, critical disability theory and QOL research. Globally, researchers found that people with disabilities have a disadvantaged when obtaining employment, accessing education and rising out of poverty. For children with disabilities, this disadvantage begins when policies are not in place to provide them with an education or create an inclusive environment. People with disabilities are less likely to complete school than their non-disabled peers and are amongst the poorest of the poor. Critical disability theory is trying to move the conversation and policy further from the medical model to an emancipatory model where people with disabilities gain empowerment and acceptance within a society. Many people with disabilities are not seen as contributing members of the family, but more a burden. Critical disability theory examines the way in which disability is seen at a societal level and reasons why people with disabilities are often excluded or stigmatized. Quality of Life research is a way to study the lives of people with disabilities to determine policies, which would aid in the successful integration and destigmatization of people with disabilities. The global literature on disability, critical disability theory and QOL research are the basis from which this research examines the lives of 10 families with children with disabilities who attend a school in Monrovia, Liberia.

## **Chapter Three**

### **The Context: Liberia**

Sierra Leone, Guinea, Cote d'Ivoire and the Atlantic Ocean border Liberia in West Africa. The population of Liberia is approximately four million with a little over 80 percent multidimensionally poor and an average life expectancy of 57 (UNDP, n.d.a). According to the Central Intelligence Agency (CIA) (n.d.), the gross domestic product (GDP) in Liberia is 2.8 billion, ranking 183 out of 229 in the world. Liberia was one of the few countries in Africa that was not, technically, a former colony of Western Europe. The American Colonization Society (ACS) resettled freed American slaves in Liberia beginning in 1821. When the former freed slaves arrived, they were met with a very diverse country comprised of 16 different tribes. Today, the Kpelle are the largest ethnic group, making up 20 percent of the population; however, English is the official language and taught in all schools. The former freed slaves constitute less than 5 percent of the population (United States Department of State, 2011). ACS resettled approximately 10,000 former slaves to Liberia and controlled the Commonwealth of Liberia until 1847 when Liberia gained independence, becoming the Republic of Liberia (United State Department of State, 2011) and Africa's first republic.

The freed slaves, known as Americo-Liberians, built schools and a university, Liberia College, along with an increased private sector (Duva, 2002). They were doing well, until independence in 1847, when it lost the financial backing of ACS. The founders of Liberia sought to create a country that was based on equal rights. However, the indigenous populations were excluded from the political process, not earning voting

rights or participating in elections until 1946 (United States Library of Congress, 1998). In addition, the Liberian government was in a lot of debt and tried to gain investment from U.S. companies, such as Firestone. Firestone used the indigenous populations as forced labor (Duva, 2002). This divide between the Americo-Liberians and the indigenous populations was the foundation for the 14-year civil war.

Some researchers argue that the Americo-Liberians were actually colonizers because of their lack of ethnic connection to Liberia. Akpan (1973) stated, "...in spite of their colour, [Americo-Liberians] were...as foreign and lacking sentimental attachment to Africa as were European colonialists..." (p. 219). Kabia (2010) took a more positive view of the relationship between the U.S. and Liberia, "...the country looks up to the US as its 'big brother'" (p. 135). Liberia modeled their constitution after the United States, the capital, Monrovia, is named after James Monroe, and John F. Kennedy Memorial Hospital is the main hospital in Monrovia. In her memoirs, Leymah Gbowee, a 2011 Nobel Prize winner for her non-violent struggle against Charles Taylor and women's rights in peace building work (Nobel Prize, n.d.), remembers watching *Sanford and Son*, *Good Times*, *Dynasty* and *Dallas*, all American television shows (Gbowee, 2011).

The power held by the Americo-Liberians and the marginalization of all other ethnicities led to a coup d'état headed by Samuel Doe, an indigenous Liberian from the Khran tribe, in 1980. The Liberians were, at first, excited to see an indigenous leader. However, their euphoria did not last long, as Doe simply changed the Americo-Liberian policies of segregation and marginalization to favor his ethnic group and his allies (Kabia, 2010). Doe was an authoritarian ruler and his preferences for his own ethnic group led to tensions between the Khran tribe and others. Doe solidified control in

October 1985 in an election characterized by fraud (United States Department of State, 2011). Doe was ultimately killed in 1990 by Prince Johnson, a rebel leader and a former follower of former president Charles Taylor.

Charles Taylor was a prominent political figure during the Doe presidency. According to Online Newshour (n.d.), Charles Taylor is an Americo-Liberian who grew up in Liberia just outside of Monrovia (Charles Ghankay Taylor, 2014). In 1974, he moved to the United States and attended Bentley College in Massachusetts, earning a Bachelor of Arts degree in economics. Online Newshour (n.d.) reported,

Taylor returned [to Liberia] in the spring of 1980, on the eve of great changes that would change Liberia and his fortunes...The economic and social disparity between the ancestors of the Americans and the native people created feelings of resentment amongst Liberians. It was this anger that helped spark a bloody coup that ultimately brought Taylor to power.

Taylor's political skills and economics background earned him a role in Doe's government; however, in 1984, Taylor embezzled over \$900,000 and fled to the United States (Newshour Online, n.d.). He was jailed in the United States, but escaped to Libya where he formed the National Patriotic Front of Liberia (NPFL). The NPFL invaded Liberia in 1989 beginning a civil war that led to a 1996 peace pact (Charles Ghankay Taylor, 2014). In the 1989 fight for Monrovia, the NPFL split into two factions with Taylor as the head of one side and Prince Johnson the head of the other. Johnson killed President Doe in 1990, after which, Johnson and Taylor fought for power until 1997 when Charles Taylor won an election (Online Newshour, n.d). According to the United States Department of State (2011), the civil war in Liberia from 1989 to 1996 was one of

Africa's bloodiest, "claiming more than 200,000 Liberians and displacing a million others into refugee camps." Charles Taylor's tenure as President was grim. Taylor did little to develop Liberia. The United States Department of State (2011) reported, "Unemployment and illiteracy stood above 75%, and little investment was made in the country's infrastructure... Pipe-borne water and electricity were generally unavailable to most of the population... and schools, hospitals, roads, and infrastructure remained derelict." During his presidency, Taylor supported the Revolutionary United Front in neighboring Sierra Leone by selling arms and supplies in exchange for diamonds (Online Newshour, n.d.); acts for which he is currently serving a 50-year jail term (Sesay, 2012). The fighting continued between Taylor and opposition factions throughout Taylor's presidency in Liberia (Charles Ghankay Taylor, 2014). In 2003, Peace Accords were signed, ending the brutal 14-year civil war.

The warring factions signed the peace accord in Accra, Ghana. Charles Taylor resigned and went into exile in Nigeria. The United Nations Mission in Liberia took over security and created a transitional government. In 2005, Ellen Johnson Sirleaf became the first democratically elected female President. A Truth and Reconciliation Commission (TRC) created in 2005 published a report in 2009 regarding the human rights violations between 1989 and 2003. Unfortunately, many of the recommendations in the report have not been addressed (United States Department of State, 2011) In November 2011, President Sirleaf won re-election in what the international community had deemed a free and fair election. The elections were relatively peaceful, bringing hope to the country that Liberia is finally free from the cycle of violence.

### **Impact of the War on Liberians**



The civil war destroyed much of the Liberian infrastructure. One person I met in Liberia told me that the only way people knew they were entering Monrovia, in the early days after the war, was because the street coming into the city was lined with candles. The reconstruction effort in Monrovia is still going on today and some parts of the interior are still waiting on the progress that has touched Monrovia, such as paved roads and electricity.

The civil war had a negative impact on Liberians' psychological well-being. "More than 250,000 Liberians died in the war, approximately one fourteenth of the population. More than one million were displaced" (Williams, 2011, p. 55). More than 38,000 child soldiers participated in the war as, "fighters, porters, ammunition carriers, cooks, and sex slaves" (MacDougall, 2013, para. 12). Stepakoff (2008) reported,

Documented atrocities included intentional hacking off of limbs, carving of initials of rebel factions into victims' skin, and ritualistic sacrifices of pregnant women and young girls. Numerous people have reported that they were forced to cut, cook, eat, and serve human flesh and internal organs, including that of their own relatives. Countless numbers of children and teenagers were forced to watch the torture, rape, and brutal murder of their parents and siblings. In many cases, family members—including children—were forced to rape, murder, and mutilate each other. During these acts, victims were forbidden to show any emotion or, in many cases, were commanded to laugh. In some instances, people who shed tears in response to these atrocities were punished by being permanently blinded. (p. 404)

It is not hard to fathom the detrimental psychological effects those acts have had on the population. Although few studies have been conducted on the psychological well-being

of Liberians, the Carter Center (n.d.) reported, "...approximately 44 percent of Liberia's 3.4 million people experience post-traumatic stress disorder (PTSD)." The lack of adequate access to and stigma against seeking mental health services has led to a population still suffering the psychological effect of war.

## **Liberia in Development**

Liberia is a fragile state (Organisation for Economic Co-operation and Development (OECD), 2011). Walker, Millar-Wood and Allemano (2009) define a fragile state as a country where, “government and state structures lack capacity and/or political will to deliver safety and security, good governance and poverty reduction to their citizens” (p. ix). Liberia is one of the poorest countries in the world with a Human Development Index ranking of 174 out of 186 (UNDP, 2013, p. 130). Liberia was ranked 182 out of 187 in 2011, which shows some gains in human development (UNDP, 2011, p. 130), but not as developed as in 1992, just after Doe took power, when Liberia ranked 131 out of 160 (UNDP, 1992, p. 133). There are only a few paved roads, routinely washed away during the rainy season, making some areas of the country accessible only by helicopter. There is little to no government sponsored public transportation. According to the most recent Human Development Report (2013), 84 percent of Liberians are multidimensionally poor (UNDP, 2013, p. 27). The percentage of people with disabilities in Liberia is unknown. Based on research reviewed in the previous chapter, it can be hypothesized that people with disabilities in Liberia are more likely affected by multidimensional poverty.

The government of Liberia systematically excludes people with disabilities in the development agenda. Liberia RISING 2030 is a development strategy that will succeed the current poverty reduction strategy. Liberia RISING 2030 is,

a strategy of broad participation and inclusive growth, allowing Liberia to build the human resource capacity needed while forging a stronger sense of citizenship, national cohesion and responsive governance. The goal is to develop and commit

to a vision and strategy for reaching middle-income status by 2030 (Republic of Liberia, Ministry of Planning and Economic Affairs, 2009).

Liberia RISING 2030 has two areas of focus: economic growth/wealth creation and socio-political objectives. The economic growth and wealth creation objectives include:

- 1) Improved standard of living
- 2) Long-term growth trajectory
- 3) Medium and long-term planning framework to guide public investment programs
- 4) Equitable distribution of income
  - a) No Liberian living in abject poverty by 2030
  - b) Strong social safety net for the disadvantaged
- 5) Middle income country by 2030
  - a) Per capita GNI between US\$2000 – 3000
  - b) Average annual growth rate of 12% - 15%. (ROL Ministry of Planning and Economic Affairs, 2009)

The socio-political objectives are:

- 1) Develop a strong sense of citizenship, unity and cohesion
- 2) Consolidate institutions of good governance
- 3) Reduce disparities and marginalization and ensure equity through policies of growth with development
- 4) Strengthen commitment to moral, ethical and accountable governance as obligation of government, private sector and citizens. (ROL Ministry of Planning and Economic Affairs, 2009)

The following is the vision of what Liberia will look like in 2030:

- No citizen should be disadvantaged as a result of gender, age, religion, ethnic origin or political opinions.
- Equitable distribution of income
- Open, democratic and accountable society, particularly individuals in leadership positions
- No Liberian living in poverty
- An established and functional social safety net should support disadvantaged persons
- Every citizen should have access to quality housing and health services within a reasonable distance. (ROL Ministry of Planning and Economic Affairs, 2009)

Liberia will not reach any of these goals without creating an inclusive environment that empowers people with disabilities. Unfortunately, the Liberia RISING 2030 strategy does not even list people with disabilities as a target group. The previous development agenda, the Poverty Reduction Strategy- Lifting Liberia (ROL 2008) mentions people with disabilities as a targeted group for services, but does not account for any progress in the *Lift Liberia Poverty Reduction Strategy Final Report: A Results-Focused Assessment* (ROL Ministry of Planning and Economic Affairs, 2012). The feigned ignorance in the development strategy and in education on the part of the government is curious and worth further investigation that goes beyond the scope of this research.

### **Disability in Liberia**

The stigma against people with disabilities in Liberia is very strong. In most countries, people with a stigma attached to them are not part of the society or even at the same level of humanity as others without the stigma. Goffman (1963) stated, “By definition...we believe the person with stigma is not quite human” (Kindle version, location 117 of 2700). Many Liberians do not understand the medical reasons for disability. These Liberians believe that disability stems from a curse due to that person or that person’s family having done something against society, another family member or the community (personal communication, October 30, 2012). Many Liberians believe that there are only three types of disabilities: physical, blind and deaf. Some Liberians also believe that many people with speech impairments have a *tied tongue*. The procedure for reversing tied tongue is to make a small incision under the tongue where the tongue connects to the base of the mouth. Some Liberians believe that the tongue is attached to the bottom of the mouth, causing the child to have speech impairment because the tongue cannot move freely. In addition, many Liberians believe that anyone with a cognitive disability is just crazy (personal communication, November 15, 2012). One employee from an American Center doing trainings for Liberian nurses and physician assistants to become mental health facilitators stated that many of the participants in the program,

...believe that mental illness is contagious. Many of them believe that epilepsy is contagious. Many of them believe that people can become mentally ill as a result of being witched or spoiling medicine law or um...doing something that is against society. Many of them believe that if you did something against society, whether it is sleeping with somebody else’s husband or incest or something bad, your

ancestors can then take revenge on you spiritually, so there's definitely that.

(personal communication, October 30, 2012)

This stigma can lead individuals to go as far as killing a baby or leaving a baby in the bush or on a trash heap. While in Liberia, I visited a foster home/orphanage where one child had been found in the bush and suffered from traumatic brain injury. However, it was unclear as to whether the injury was sustained before or after being abandoned. Hence, in Liberia, there do not appear to be many children with intellectual disabilities because they might have been abandoned, intentionally killed, or they die of natural causes. The child mortality rate in Liberia is one of the highest in the world, with 15 percent of children not reaching their first birthday (United Nations Children's Fund (UNICEF), 2012). There is no data on children with disabilities or the mortality rates of children with disabilities in Liberia.

The National Union of the Organization for the Disabled (NUOD) and the National Council on Disabilities (NCD) are two Liberian national disability rights organizations. The substantive impact of these organizations is unknown. NCD works on policy and tries to help create inclusive policy (personal communication, November 15, 2012). NUOD works together with disability rights groups around the country to promote the rights and livelihood of people with disabilities (personal communication, November 8, 2012). There are many difficulties for both organizations when they try to garner support from the government and development agencies

### **Education in Liberia**

The conflict destroyed most schools in Liberia. School construction has been a priority for the government. “The literacy, advanced education and skills of the majority of Liberia’s population is dramatically low, due to the decimation of the educational system brought on by Liberia’s conflict” (ROL Ministry of Planning and Economic Affairs, 2011, p. 9). The ROL Ministry of Education (2007) reported that, “...an estimated 80 percent of schools were destroyed” (p. 7). Only 26 percent of schools had water and 35 percent had latrines in June 2004 (ROL Ministry of Education, 2007, p. 7) and the most recent school census 2010/2011 stated that, “More than 80% of children...who should have been in school were either conscripted by...armed factions or were prevented from pursuing a normal life” (ROL Ministry of Education, 2011a, p. 35). The ROL Ministry of Education (2007) also found the textbook ratio for students was 27:1, many students do not have desks, chairs, or chalkboards, and teachers were not paid enough to buy a bag of rice and had to seek out secondary employment. In addition, an estimated 62 percent of teachers were not qualified to teach (ROL Ministry of Education, 2007). Gross enrollment rates declined drastically between 2000 and 2002 with decline in girls’ enrollment from 72.5 percent in 2000 to just 35.5 percent in 2002 and for boys, the gross enrollment was 73 percent in 2000, dropping to 48.5 percent in 2002 (ROL Ministry of Education, 2007). Lack of government funding, schools imposing user fees, insecurity, and poverty led to decreased enrollment levels (ROL Ministry of Education, 2007). It is safe to say that at the end of the war, the education system in Liberia was non-existent.

Sexual violence against women and girls was used during the conflict and continues to be a major problem today (United Nations, n.d.), including in schools. Girls



are often forced to perform sexual favors for male teachers for their grades with little to no disciplinary action (Dahn, 2008). The ROL Ministry of Education's (n.d) Education Sector Plan acknowledges that sexual based violence is an issue; one objective is "to make...provisions and arrangements that result in the school...being clean, sanitary, violence-free and sufficiently conducive for all students, especially girls, to feel safe and at ease" (p. 70). The strategy is to, "develop and implement strategies that deal with sexual exploitation and violence in school ensuring the involvement of PTAs [Parent/Teacher Associations] and the community" (Ministry of Education, n.d., p. 70). This shows that the government recognizes that sexual based violence in primary school is a problem; however, the research shows that the implementation of the strategy has yet to be achieved (Dahn, 2008; United Nations, n.d.).

Over the past few years, the Government of Liberia (GOL) and various agencies have worked to develop a school system from the ground up. Now, many different educationally focused companies and agencies are engaged in a campaign to rebuild many of the schools, retrain teachers, and decrease student to teacher ratio and student to textbook ratio. One employee at an American development company stated that there are over 3,000 newly trained teachers and observed, "I have seen some very impressive teaching from people from the program" (personal communication, November 28, 2012). In 2009, 461 students had graduated from the Rural Teacher Training Institutes pre-service training and another 900 graduated from the in-service training programs (ROL, 2010). In addition, this employee stated that the focus on reading and math in the lower levels of primary education has produced positive result (personal communication, November 28, 2012). The employee continued, "...the work in reading and math is also

very encouraging and as a result of that, students in the schools are learning to read” (personal communication, November 28, 2012).

One UN employee reported that the ratio of student to textbook has decreased from 27:1 to 2:1 (personal communication, November 20, 2012). Another success in the school system is the enrollment of students. According to the most recent census, enrollment in school has increased across the board, as well as with increased gender parity (ROL Ministry of Education, 2011, p. 1). The ROL Ministry of Education (2011a) stated that the primary completion rate has also increased from 21 percent in 2002 to an estimated 62 percent in 2008. In the 2010/2011 school census report, the increase was again dramatic, with a range of gross completion rates between 42 and 113 percent throughout the country. The gross completion rate of 113 percent is due to the dramatic increase of the over-aged student population in Liberia’s post-conflict setting. Increased enrollment and completion is a step forward for a school system facing many challenges. The Liberian education system was essentially rebooted after the war in 2003. The Government of Liberia has made some strides in education in terms of teacher pay, student to textbook ratios and getting students in the classroom. For one of the poorest countries in the world, these successes are monumental towards creating a sense of normalcy after a conflict that destroyed so much. The education system is making progress *small, small*, as a Liberian would say.

Unfortunately, even with those successes, there are still major hurdles to overcome. Basic school infrastructure is still a problem. Many schools, even newly built schools, remain without a latrine or desks (personal communication, November 28, 2012). In addition, the increase in enrollment and teacher shortage have led to severe

overcrowding in many schools and due to that conflict, a majority of students in pre-primary and primary are over-aged (ROL, 2010). Teachers still face many difficulties, especially concerning actually obtaining a salary. Teachers' pay has increased, but one employee at an American development company stated, "Teachers can be away from the school for up to a week just getting their pay. If that happens once a month, that's one out of four or five weeks gone" (personal communication, November 28, 2012). The employee continued, "There is no reliable payroll... there are ghost schools, there are ghost teacher schools, even districts, and that really needs to be addressed." Further, "[new teachers] frequently take a long time to get on the payroll" (personal communication, November 28, 2012). There has been an increase in the number of teachers granted the most basic teaching certificate, but those teachers are still not necessarily qualified to teach. A development worker in the field of teacher training stated that many of the teachers attempting to enter the Rural Teacher Training Institutes (RTTIs) are unable to pass a basic skills test, even though a high school diploma is required just to apply to the RTTIs (personal communication, November 28 2012). The most recent census stated that, "the proportion of trained teachers ranged between 40 and 60 percent at all levels" (ROL Ministry of Education, 2011a). One UN employee would wear the tee shirt of the agency in the field and ask students to read the shirt. The employee stated the students could read the letters individually, but could not form the word for that agency. The UN employee then recounted this story to an MOE official to which the MOE official responded, "in a somewhat desperate tone, she said, 'You will be even more disappointed if you asked the teachers to do it'" (personal communication, November 13, 2012). This raises the question of the quality of education. As stated in the

last section, the gross enrollment rates have risen drastically in the last few years, yet the teachers are still unqualified and have difficulty passing basic skills tests. Over-aged youth in primary classes, adults in secondary classes, lack of materials, overcrowded classrooms and low teacher pay overshadow the Liberian education successes. It is important to recognize that these are the identified challenges. There are individuals who work in key positions that understand the problem and are trying to chip away at each one.

### **Education and Disability in Liberia**

Even within this climate of change and the renewed focus on the education sector, children with disabilities do not attend school. In the Education Sector Plan (ESP), the Government of Liberia recognizes the need to include students with disabilities in an inclusive environment (ROL Ministry of Education, n.d.). On paper, Liberia has begun to use terms like *inclusion*. The Education Law and the Children's Law vaguely define special education and inclusion.

The Liberian government does not define inclusion so much as simply state what it does:

The concept of inclusion is one that promotes increased positive social interaction and learning effects, as has been supported by several studies. Furthermore, inclusion advances equality and participation; it thus leads students to have a greater sense of belonging and acceptance. In this light, county school boards shall strive to redress any mechanisms, which might exclude children from equal access to, participation in, and outcomes of schooling based on language or culture, gender, physical, intellectual or emotional state or socio-economic status. (Republic of Liberia Ministry of Foreign Affairs 2011, pp. 63 - 62)

The Republic of Liberia (2011) Children's Law stated,

County local government authorities with appropriate support from central government shall provide to children with disabilities and those responsible for their care, free appropriate assistance to ensure that [children with disabilities] have effective access to and receive education, training...reparation for employment and recreation opportunities in an environment that is physically and socially friendly...Every child with disabilities shall access and benefit from an inclusive education system offering education that is responsive and supportive to the child's learning needs and talents in a participative and non-discrimination manner. (Republic of Liberia, 2011, p. 22-23)

The Republic of Liberia Ministry of Foreign Affairs (2011), who is created for the current education law, defines special education as “the education services provided for those who are highly gifted and those who are physically and mentally challenged” (p. 6). Unfortunately, these are trumped by a clause in the same 2011 education law that states, “A school may exempt a child entirely, partially or conditionally from free and compulsory school attendance if it is in the best interest of the child, *especially those with disabilities* [emphasis added]” (Republic of Liberia Ministry of Foreign Affairs, 2011). This specific clause is in violation of both the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, both of which Liberia has ratified.<sup>4</sup> In addition, if *any* child is denied the right to attend school, Liberia will never achieve the goal of universal primary education or any of the Education for All goals.

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<sup>4</sup> The CRC was ratified in 1993 (UNICEF, 2009) and the UNCPRD was ratified in 2012 (United Nations, n.d).

Many NGO and development workers in the field of disability rights believe that there is a lack of political will to include children with disabilities. One employee of a European NGO stated,

...the absence of focus on disability, probably is a kind of political issue. There is a general amnesia about disability, for me, because disability is so linked to the war, so these people want to forget about the war. They want to do as the war was not here, it's not really a good strategy because the war is here; the war is in the belly of almost all Liberians. (personal communication, November 13, 2012)

This participant and I had many conversations about the impact of the war on the Liberian psyche. This participant confirmed my belief that many Liberians want to ignore the psychological issues that face every Liberian because of the violence of the war. Liberians want to forget the war and pretend as though it never happened. Another employee of an American Center recounted a story of when this person was in a meeting regarding the second Poverty Reduction Strategy (PRS):

I brought to the table the fact that we are going forward with the PRS when we have an education law that is very contrary to that. They started yelling at me. The people from the MOE started yelling at me and saying that it's not all disabilities, it's just certain ones and it's about degrees and we have no problem bringing people with physical disabilities into the classroom, but you can't expect us, this is not America, to be educating people who are stupid and dumb and they go on and on ... so it's not that the policy of inclusive education is not feasible, it's very feasible, but there is a lack of political will to make it happen. (personal communication, October 30, 2012)

When discussing the challenges the Liberian education system faces, political issues and the role of the UN, a UN employee stated,

We can't force the government to do something; it has to be the MOE asking us to do it. When they ask us to do it, we also push that agenda, but if they are not asking us to do it, we know that it is important, but we can't force them. (personal communication, November 20, 2012).

The Liberian education system has overcome some hurdles, but there are still many more to overcome.

The 2010-2011 school census reports that there are 10,931 students with disabilities out of a total population of 1,542,398 in the public schools (K-12) throughout Liberia (ROL Ministry of Education, 2011a). These numbers are hard to believe based on my experience in Liberia and the experience of others. One MOE employee stated, "I don't give much credence to the census because the results were cooked, I don't think they actually went out [to the schools]" (personal communication, November 27, 2012). Another Liberian who works in teacher training asked me, "How do you teach those children?" when he was referring to children with disabilities (personal communication, November 28, 2012). When I asked one high-level education advisor about students with more moderate to severe cognitive disabilities in the public schools, this person stated, "We have those kinds of people in Liberia?" (personal communication, November 28, 2012). Another employee at an American development company stated, "I've been in quite a lot of classrooms, I am not conscious that I have ever seen a handicapped child" (personal communication, November 28, 2012). The personal experiences of the MOE staff, people working in development and my own observations do not support the school

census report, giving more credence to lack of access to students with disabilities than acceptance that they are in the classroom.

### **School for the Blind**

The School for the Blind is the only government-run school for children with disabilities. It is a boarding facility located about an hour outside of Monrovia in Virginia County. According to the 2010-2011 school census report, there were 42 students with 11 teachers (ROL Ministry of Education, 2011a). The 2012-2013 school year saw a drop in enrollment to 37 (personal communication, November 27, 2012). The School for the Blind opened in 1977 with 26 students coming from four different counties. It is a residential program for students through grade six. Due to the civil conflict, the school closed from 1989 until 2003 (personal communication, December 8, 2012). The school currently educates students through grade six, when they are sent to private schools, if their family is willing and can afford the school, or are forced to, “drop by the wayside because of no support” (personal communication, November 27, 2012). The Ministry of Health and Social Welfare ran the school until 2005 when the Ministry of Education took over control of the school.

The School for the Blind is underfunded, poorly managed, and surrounded in controversy. The former principal passed away in September 2012 from AIDS and his widow blamed the students for casting a spell on her husband (personal communication, September 2012). When I visited the facility in November 2012, the wife of the former principal was living illegally in the back portion of the property with a former student who refused to leave. The wife had transfer papers to go to another school, but the



Ministry of Education lacked the ability to remove her from the property (personal communication, November 27, 2012). The lack of funding has left the only Perkin's Braille typewriter broken, the students without the proper Braille translated materials, and an acting principal who lacked the proper resources to do her job effectively (personal communication, November 27, 2012). The stipend to pay teachers and staff is often late and there is a fear that in an emergency, the school would not be able to afford a taxi to get to a medical facility (personal communication, November 27, 2012). The School for the Blind is an example, the only example, of the Ministry of Education's attempt to educate students with disabilities. The corruption, ignorance and lack of funding of programs for people with disabilities are in plain sight. The School for the Blind is a microcosm of the larger problems facing children with disabilities in Liberia.

### **Other Boarding Facilities**

There are many boarding facilities for children with disabilities in Liberia. A majority of them focuses on students that are hard of hearing or suffer from blindness. There were rumors of a boarding facility for students with cognitive disabilities, but I was never able to locate a contact or visit the facility. There is also little to no regulation of the boarding facilities. Many of my sources, participants that work in the field of special education, stated that the schools were poorly managed and had become dumping grounds for children with disabilities. Consequently, abuse is rampant. One European NGO employee that works closely with the disability movement in Liberia stated,

...all these [boarding] schools maintain unacceptable standards as far as education, as far as security, as far as abuses, as far as care, they should be closed.

In many cases they become orphanages because they claim these children do not have parents, which is not true in many, many cases, there are probably a few cases, so it becomes a segregating school without any links with that family because they come with different counties and they lost contact with regional communities. So they become fully dependent on these institutions that are not able to provide even quality services.... (personal communication, November 13, 2012)

The absence of research on the boarding facility, combined with the lack of regulation and enforcement, leaves an undesirable picture of the schooling for children with disabilities in Liberia.

### **Chapter Summary**

Liberia is a diverse nation with a troubled past and questionable future. Most Liberians are multi-dimensionally poor. The civil conflict left the country devastated in every dimension. People with disabilities are on the lowest rung of the economic ladder; without education, they will remain there. This chapter described the context in which Liberians live and children are educated. It sought to explore the many challenges children with disabilities face when they are allowed to enter the classroom, as well as point out the difficulties children with disabilities encounter outside the educational setting. The context of Liberia is important to understand when discussing the Center's influence on the lives of their students.

## Chapter Four

### Research Methodology: A Qualitative Case Study

This research uses a qualitative case study method to answer the research question. Merriam (2009) describes qualitative researchers as being “interested in understanding how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences” (p. 5). In addition, Creswell (2007) states, “*Qualitative research* [emphasis in the original] begins with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem” (p. 37). Creswell (2007) continues by defining the qualitative process, “To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is inductive and establishes patterns or themes” (p. 37). In this particular study, I look at an educational institution’s role in influencing the QOL for the families with children with disabilities who attend the Center. This reflects my assumption that education increases QOL for students with disabilities and their families. The research takes place in the natural environment of the school and home visits. I focus on the experiences of the many people associated with the Center in order to determine how they have constructed their world in alignment with the definition of qualitative research.

My research is a case study design. Yin (2009) defined case study as, “...an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are

not clearly evident” (p. 18). Merriam (2009) stated, “A case study is an in-depth description and analysis of a bounded system” (p. 40) and Stake (1995) added that “Case study is the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances” (p. xi). My study is bounded by the use of one school. I look at the current phenomenon and social issue: special education in a developing country. In addition, the Center provides a unique case because of their claims that they have improved the lives of their students and have created a more inclusive environment within the surrounding community. Lastly, it is in a real-life context, as I volunteered at the Center and lived in Liberia. I chose case study over other forms of qualitative research methodologies because of the unique case the Center presents. Case study provides the tools and procedures necessary to understand better the lives of students that the Center impacts.

Many researchers point out that qualitative research design must be flexible and responsive to the changing needs of the study (Berg, 2009; Creswell, 2007; Merriam, 2009; Yin, 2009). Creswell (2007) states that an emergent design “means that the initial plan for research cannot be tightly prescribed, and that all phases of the process may change...after the researcher enters the field...” (p. 39). This was true in this study. At the proposal stage, I stated that I would attempt to interview students; however, only one of the students, Kevin, has verbal skills. I interviewed him, but the other students’ disabilities made communication difficult. With the exception of Kevin, the students could vocalize words like “mama” and “papa,” shake their heads yes or no, or use a few American Sign Language (ASL) signs. This made it impossible to conduct in-depth interviews with the students. Instead, I relied on observations and non-verbal forms of

communication, such as laughing, smiling, crying, etc. to determine the students' emotions toward the school. Schalock *et al.* (2002) pointed out, "...in many instances it may be necessary to identify personal choices using an individual's nonverbal responses, particularly when language is limited" (p. 459). Following Schalock's advice, I used observations, schoolwork, personal interaction and non-verbal social cues, such as a smile, crying or screaming as indication of an emotional state. I would then verify with a parent or employee of the school, if I had questions regarding a child's emotional state at that moment.

According to Yin (2009), case study research answers the question of *how* or *why*. This is another reason case study appears to be the best method for conducting my research. This research seeks to better understand how an education institution can influence the quality of life of its students and their families in the domains list in the last section on QOL. Following Yin's case study methodology, I answer the following research question: *Based on caregiver responses, and taking into account the Liberian context, how does The Alliance Center for Children with Disabilities influence the quality of life for its students and the students' families?*

The design of the case study will be a single-case and embedded design. According to Yin (2009), a single-case design can be conducted if the case meets one of five requirements: a critical case testing a well-founded theory, a unique or extreme case, a representative or typical case, a revelatory case, or a longitudinal case. My case is a unique case because there are few opportunities in Liberia for students with disabilities to attend school. The Center is also an interesting case because of the connection the school has to the community. My case study will also be embedded. Yin (2009) describes an

embedded case study as involving, “more than one unit of analysis” (p. 50). I will have one case, the Center, with 10 families as the units of analysis.

There are weaknesses to a design that is single-case and embedded. A major concern for a single-case design is that the case may turn out to be not what the researcher thought. Yin (2009) suggests that the researcher ensure the careful investigation of the case, “to minimize the chances of misrepresentation and to maximize the access needed to collect the case study evidence” (p. 50). In preliminary investigation of the Center, I spoke with five people: The executive director of the non-profit that primarily funds the Center, the Director of Special Education for Liberia, a former Peace Corp volunteer that had recently returned from a visit to the Center, and an economic consultant for the Government of Liberia, all of whom corroborated the idea that the Center has increased the social status and quality of life of its students and that this is a unique case in Liberia. These conversations led me to the decision to focus completely on the Center, rather than explore the few other institutions in Liberia. Embedded design can sometimes distract the researcher from looking at the whole picture. Yin (2009) points out that a major concern of embedded design is when, “the case study focuses only on the subunit level and fails to return to the unit of analysis” (p. 52). By employing a framework with specific domains and focusing my interviews on those domains, I believe I have focused on both: each individual family’s quality of life, as well as the influence the Center has had on that quality of life without an over-emphasis of one or the other.

### **Setting and Rationale**

The Center is located in Paynesville, a suburb of Monrovia, near the Red Light District of Monrovia. The Red Light District is named after the one hanging red light at

the main intersection that has not worked since the war broke out (Page, 2003). Red Light is a labyrinth of umbrellas and makeshift stores buttressed up against large concrete structures that sell anything one can imagine. Under the umbrellas, men and women (mostly men) have computers, printers, and copy machines that serve as a “Kinko’s” for the surrounding community. Others are selling electronics, food, water, soda, lapas (fabric), shoes, etc. The Center is located just behind this commercial chaos, down a dirt path that passes at least three different schools, all private. The local public school is approximately a mile from the Center.

The Center is a concrete structure with one main room, one office, three classrooms and kitchen. Two of classrooms contain desks or benches for the students and the third classroom is a storage/lunch room where the students sit on the floor. The kitchen has shelves to store cookware and a small coal stove. A water pump, which sits adjacent to the open kitchen, was donated by a few INGOs and provides a small source of income for the school, as they charge a nominal fee to the community to obtain clean water from the pump.

Another center for children with disabilities was started in the Bududuram Refugee Camp in Ghana by parents and caretakers of children with disabilities. David, the current center’s director, stated,

We, who were parents of children with disabilities and the other organizations that were in the camp and I talked to a fellow parent of mine who had a disabled daughter and since our kids are not being looked after by UNHCR, neither by the camp authorities and we could ask our friend, a French physiotherapist to please assist us in helping us to start a little project where we could have our disabled

children together and we teach them basic education, like the alphabet, numbers.... (personal communication, December 6, 2012)

In 2009, David and his family moved back to Liberia and settled in Paynesville. David stated that he and his wife, Praise, conducted their own *child-find* activity upon their return to Liberia to see if the Center from the refugee camp was needed in the Paynesville area. They walked around the community asking about the area and where children with disabilities lived. David first met Zack and slowly he realized the need for a Center in the Red Light area of Paynesville. The Center opened on December 11, 2009 (personal communication, December 6, 2012).

The Niapele Project monetarily supports the Center and a short discussion about their history is important to understanding the context. The Niapele Project was founded in 2007. It was started by two former volunteers, “who identified the needs at the Buduburam Refugee Settlement in Ghana” (Niapele Project, n.d.b). The mission states:

The Niapele Project’s mission is to promote sustainable strategies for the empowerment of vulnerable children, by supporting community-based initiatives. We work in partnership with communities, assisting them to fulfill the needs they have identified, through the development and implementation of initiatives that aim to create the necessary conditions for children and their communities to thrive. (Niapele Project, n.d.b)

The Center works together with the Niapele Project and all the Center staff are Liberians that have an interest in serving students with disabilities. The relationship between the Center and the Niapele Project is horizontal. The relationship between the



Niapele Project and the Center will be discussed in further detail in the findings and conclusion.

### **Participant Selection**

I selected my participants based on their connection to the disability movement in Liberia. The families were selected based on enrollment of at least one child older than six in the Center's program. There was only one child's family who was not selected for participation, as the child was only four years old. All 38 of the interviewees were adults and were asked to voluntarily participate in the study. Kevin was 16 and his parents gave permission for the interview. If a participant traveled to me, I offered a one-dollar bill in order to counter the cost of travel. I volunteered at the Center, so access to students and family members was not difficult. I also volunteered with the Ministry of Education, Division of Special Education, which gave me increased access to the inner workings of the Liberian education system at the government level and exposed me to policymakers, some of whom I was given the opportunity to interview. My sampling was purposeful (Merriam, 2009) and I used snowball sampling to find additional interviewees. I began with interviewing caregivers of each of the students and was then introduced to other caregivers or friends who had insight to the life of the family and the Center. Since I volunteered at the Ministry of Education, the director of Special Education was able to put me in contact with NGOs and INGOs with employees who were willing to speak with me. I feel I obtained saturation of my study because my participants, especially those outside the Center, voiced many of the same concerns about people with disabilities in Liberia. I also achieved saturation at the Center because I interviewed all employees and all parents or caretakers willing to sit and speak with me. Lincoln and Guba (1985) point

out, “in purposeful sampling the size of the sample is determined by informational considerations. If the purpose is to maximize information, the sampling is terminated when no new information is forthcoming from new sampled units; thus redundancy is the primary criterion” (as cited in Merriam, 2009, p. 80). In the end, I interviewed people with a variety of different roles that directly and indirectly affect the lives of these 10 families:

**Table 3: Number of Interviewees and Roles**

Role:	Amount:
Student	1
Caretakers	12
Administration	4 (two administrators are also a parent)
Teachers	3 (one teacher is also a parent)
Employees of the Center	3
INGOs/NGOs/ Development Agencies	9
Government of Liberia Employees	6
Community members	5

### **Research and Disability**

There are many considerations when conducting research with children, especially those with disabilities. According to the Institutional Review Board (IRB) Guidebook (1993), children and persons with cognitive impairments are vulnerable populations. In the case of research with this population, it is important to ensure minimal risk, which will be defined as, “the probability and magnitude of harm or discomfort

anticipated in the proposed research are not greater, in and of themselves, than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations...” (IRB Guidebook, 1993). This research did not create more than a minimal risk for participants. The interviews were held in places where the participant felt safe, such as the Center or at their home, if desired. Verbal consent was obtained from either the parent or guardian for participation in the study of their child.

### **Data Collection Procedures and Analysis**

Interviewing is an art. The researcher is taking the ideas, thoughts, and feelings of the participant and creating an analysis that has the potential to distort those thoughts, feelings, and ideas. It is important that the original voice of the participant is heard and understood. Yin (2009) stated that interviews are, “one of the most important sources of case study information” (p. 106). The researcher must have the ability to really listen and to understand what the participant is saying. Rubin and Rubin (2005) affirmed this, “Through qualitative interviews you can understand experiences and reconstruct events in which you did not participate, from becoming a fundamentalist Muslim to organizing a mine workers’ union, from participating in a beauty contest to fighting a war in central Africa” (p. 3). I have used the voice of my participants as much as possible to create the most detailed picture possible within the parameters of this research. While interviewing, I limited my own voice and let the participant answer questions as thoroughly as he or she wanted to. If I had an additional question during the participant’s answer, I would write it down on a piece of paper and ask it when the participant completed his or her answer.

Rubin and Rubin (2005) describe interviewees as conversation partners, “which has the advantage of emphasizing the active role of the interviewee in shaping the discussion and in guiding what paths the research should take” (p. 14). They see the interview as “co-operative experience, as both interviewer and interviewee work together to achieve a shared understanding” (p. 14). In contradiction to this idea, Yin (2009) argues that interviews have “two jobs: (a) to follow your own line of inquiry...(b) to ask your actual (conversational) questions in an unbiased manner that also serves the needs of your line of inquiry” (p. 106). I see my interviewees as conversational partners that will add critical information to the research. I understand my research to be a mix of the laissez-faire approach of Rubin and Rubin (2005) and the rigidity of Yin (2009). In order to do this, I asked all the questions on my interview protocol, but was also flexible enough to add questions when the time arose in the interview, for example, to clarify a religious activity or an unknown word or phrase.

Incorporating the ideas of both Rubin and Rubin (2005) and Yin (2009), I conducted semi-structured interviews with all my participants. I interviewed at least one primary caretaker for each student and two in the case of Adam and Denise. I interacted, but did not conduct a formal interview with the biological mother of Patricia. To gain an understanding of the political process and the climate for disability advocacy in Liberia, I interviewed policymakers, and employees from various NGOs, INGOs and development agencies. These interviews lasted approximately forty-five minutes to an hour and a half. I had a basic protocol, but let the conversation develop as the interview continued. Below is copy of my basic protocol.

**Table 4: Semi-Structured Interview Protocol**

Opening Questions		<ol style="list-style-type: none"> <li>1. What is your job? How often do you work and on what days?</li> <li>2. What is your educational background?</li> <li>3. How old is your son or daughter that has a disability?</li> <li>4. How long have you lived in Monrovia? If you moved from another country, why did you move? Was your child treated differently there than in Monrovia?</li> <li>5. How long have you known about the Center and how long has your child attended the Center?</li> <li>6. How did you come to hear about the Center?</li> <li>7. What is your child's disability? How did he or she become this way?</li> </ol>
Quality of Life Framework Dimensions		
Emotional well-being	Safety	1. How has the Center changed your life? How do you think it has changed your son or daughter's life?
	Spirituality	2. Do you like the program for your son or daughter and why?
	Happiness	3. Before your son or daughter came to the Center, what did he or she do?
		4. What does your child do when he/she is not at the Center?
		5. Do you think your child is happy? Do think your child is satisfied being enrolled at the Center?
		6. What are some of the difficulties you face when trying to care for your child with disabilities?
		7. Do you receive any support from the government?
		8. How do you cope when you encounter a great difficulty with a child with disabilities? Do you look to religion or something else?
		9. Is this the same way you cope with other difficulties in your life?
Inter-personal relations	Intimacy	1. Does other people's reaction to your son or daughter's disability limit the activities you allow him or her to do?
	Affection	2. Does your child have friends that he or she sees outside of the Center?
	Family	3. How do other members of the family treat your child?
		4. Do you treat your child differently than your other children? Give them more or less of something?
		5. How do you discipline your child with a disability?
Material well-being	Ownership	1. What kind of job do you think your child can get?
	Financial	2. Do you think your child is better off, worse off or the same as other children his or her age financially and in terms of food? Why? How does enrollment at the Center affect your child's future, in your opinion?
	Security	3. What is a successful person? Do you think your child can be successful?

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	Food	
Personal development	Education	1. Can you describe your child's daily routine?
	Skills	2. What are some of the skills your child has and what are the greatest challenges?
		3. Has the Center helped ease those challenges? In what ways?
	Fulfillment	4. What are some skills or things you wish the Center would focus more on in your child's education?
		5. What kind of potentials has the Center helped your child develop?
		6. If there are other children, do they attend school?
Physical well-being	Health	1. Can you describe your child's daily routine?
	Nutrition	2. What are some environmental constraints which make it difficult for you in your immediate neighborhood?
		3. What are some of your fears that you have for your child? Any about nutrition?
	Recreation	4. Have you ever spoken to a bush doctor about your child's disability? What did he do or say?
		5. Have you ever tried to "cure" your child of their disability?
	Mobility	6. Do you have access to healthcare facilities to help care for your child's health?
Self-determination	Autonomy	1. Do other people's reactions to your son or daughter's disability limit the activities you allow him or her to do?
	Choices	2. Do you let your child make decisions about his or her life?
	Decisions	3. Does your child make his or her own choices, such as going out around the community, buying a donut, or spending money you give to him or her?
Social inclusion	Acceptance	1. Do you think children with disabilities should be included in regular school?
	Status	2. Do you belong to a church or mosque and does your child attend church or mosque with you? How do others in the church treat him or her?
	Supports	3. Do you worry about how other people treat your child?
		4. Do you think your child will ever get married? Find a job? Be respected by the society?
	Work	5. Who takes care of your child when you are away?
		6. Does your child play with other kids in the community, like football or games?
Rights	Privacy	1. Why doesn't your child attend the regular public school?
	Voting	2. Does your child have access to the same things that all other children have access to?
	Access	3. Do you think the government is doing a good job of creating a climate where children with disabilities can go to school?

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For caretakers, I asked all the questions, but for all other interviews I used a subset of questions, for example, for policymakers, and NGO, INGO and development agency workers, I used the questions from the social inclusion and rights domains and focused more on general aspect of disability in Liberia if they did not have any knowledge of the Center.

### **Observations**

Merriam (2009) identifies four possible types of observation: complete participant, participant as observer, observer as participant and complete observer. During my field research, I was a meld of a participant as observer and observer as participant. Participant as observer is defined as, “The researcher’s observer activities, which are known to the group, are subordinate to the researcher’s role as a participant” (Merriam, 2009, p. 124). I volunteered at the Center three days a week, approximately six hours a day, which made me a participant as observer. While volunteering, I observed the daily activities and took reflective field memos on the different interactions and activities that occurred. An observer as participant is defined as, “The researcher’s activities are known to the group; participation in the group is definitely secondary” (Merriam, 2009, p. 124). I conducted more structured observation with video for approximately one hour and several informal observations where I took notes.

Problems with observations:

There can be problems associated with observations. Creswell (2007) lists five difficulties associated with observations.

- remembering to take field notes
- quoting participants accurately in the field notes

- determining the best time to move from nonparticipant to participant
- being overwhelmed at the site with information
- learning how to funnel the observations from the broad picture to a narrower one.

(p. 139)

By videotaping a partial day and having a notebook with me most of the time, I was able to capture my thoughts with the field notebook and re-watch the video.

In addition to these five items, Yin (2009) argues that bias is a major problem with participant observation, which will be addressed in the next section on validity. He explains bias through four possible scenarios:

1. The researcher may become too close to the participants and instead of being an observer take the role of an advocate.
2. The researcher could become a supporter of the organization or group.
3. The researcher might become too much of a participant and forget his or her role as an observer.
4. If there are too many sites for the researcher to visit, it might be difficult to visit all of them and complete the study.

While conducting my field research, I became very close with all the students, staff, and parents of the Center. I am also a supporter of the organization, but my findings are based on the interviews and I employ the voice of the participant whenever possible to ensure that my bias for the Center does not compromise the integrity of the study.

I was a volunteer at the Center and helped in many ways; for example, conducting staff trainings on disability, developing a morning calendar routine with a weather chart and making suggestions for alternative disciplines for the students, such as positive



behavior reinforcement. I did not make these suggestions until several weeks into my fieldwork and was able to maintain my observer status.

### **Document Review**

I reviewed various documents, including student work, Liberian school curriculum and a development agency's curriculum for teacher training. The students' work gave me perspective on what they were retaining in the classroom. The Center attempted to follow the Liberian school curriculum and the development agency is a major source of funding for the Teacher Training Institutes around Liberia. I made copies of the students' work and the school curriculum. I took field notes on the teacher-training curriculum.

### **Coding and Analysis**

I recorded all of my interviews and followed-up with several participants via email. After each interview, I took notes based on how the participant presented him or herself, whether they felt comfortable and in what environment the interview took place. Rubin and Rubin (2005) suggest doing this so the interviewer can remember important "physical gestures, for example, a shrug of the shoulders..." (p. 204). Many of the parents appeared nervous during my first interview. To ensure that I was not misjudging their cultural norms as nervousness, I asked some of the same questions when conducting the home visits. Many of the parents seemed more at ease during the second interview than in the first. I transcribed all the interviews verbatim and included notes on the length of time the respondent took to answer a question and body language. In the analysis process, these gestures can be important to creating a very rich and thick descriptive picture of the case, as many researchers suggest (Berg, 2009; Creswell, 2007; Yin, 2009). For my

observations, I took very detailed field notes and used the same techniques as I did with my interview transcriptions.

There is so much information that the informants give to the researcher through words, gestures, long pauses, etc. that it is hard to know which are relevant to the research. In order to identify important points, I used two steps to coding my data. I used *open coding* and then *analytic coding*. Each of the steps helps the research to focus in on the parts of the interview that are important to answering the research question.

Merriam (2009) describes open coding, “As you read down through the transcript...you jot down notes, comments, observations, and queries in the margins. These notations are next to bits of data that strike you as interesting, potentially relevant, or important to your study” (p. 178). I re-read all the interviews, jotting down notes in the margins, such as connections that could be made to observations or documents or to theory, for example, when a parent stated that his or her child was accepted in the community. I would look through my field notes on the home visit to see how the child was acting and if the child appeared to be accepted in the community because he or she was interacting with other community members. These notes helped to make the connections between the interview and observations or documents, as well as make a closer connection to theory.

After completing the open coding, I reviewed each of the interviews for specific examples that connect to each of the domains. During this process, I followed analytic coding, following suggestions by both Berg (2009), and Rubin, and Rubin (2005).

1. “Ask the data a specific and consistent set of questions” (Berg, 2009, p. 354).

My research question helped to guide my analysis of the data and my coding

technique brought my analysis back to the QOL framework. While coding, I focused on when participants would discuss areas of influence in each domain, such as a parent stating that he or she became more accepting of his or her child due to the Center or that he or she better understood how to care for his or her child because of the connection to the Center.

2. “Analyze the data minutely” (Berg, 2009, p. 354).

Berg (2009) suggests that analyzing data is like writing a school paper. “Coding is much like the traditional funnel used by many educators to demonstrate how to write papers. You begin with a wide opening, a broad statement; narrow the statement throughout the body by offering substantial backing; and finally at the small end of the funnel, present a refined, tightly stated conclusion” (p. 355). This funneling process is representative of my two-step coding. In the open coding, I looked for big ideas that *pop* out to me, while in the more analytic coding, I used themes and concepts from the QOL framework. During the analytic coding phase, I used Rubin and Rubin’s (2005) idea of concepts, themes, events, and topical markers. Concept is a “word or term that represents an important idea to the research (p. 207). I used each of the domains in the QOL research as concepts when coding the data. I would highlight when an interviewee discussed a domain, for example, when a caregiver would discuss the emotional state of the family due to the connection to the Center. Themes are “summary statements and explanations of what is going on” (Rubin & Rubin, 2005, p. 207). Influence on the QOL was a theme for which I actively looked. When identifying influence, I made sure that the influence was due to the Center and not other outside entities. For example, when Denise’s grandmother walked around the community threatening violence or a curse if

anyone harmed Denise, I marked this as an outside influence because Denise's grandmother did not do this because of the Center. However, when Zack's father stated that he was surprised that Zack could learn and had more hope that Zack might get a job in the future, I marked this as influence from the Center because without the Center, Zack's father would have not had those feelings. Events are, "occurrences that have taken place" (Rubin & Rubin, 2005, p. 207). During the coding process, I marked events that might be examples of influence on the QOL for the Center. One event that was identified was the closing school year presentation where David remarked that many of the community members were surprised to see that the children could learn or when Praise and David had discussions with community members. Topical markers are the names, people, address, or public laws or bills mentioned (Rubin & Rubin, 2005, p. 207). When identifying topical markers in the transcript, I would look for a participant's discussion on laws or government. Each of these ideas helps to break apart the interview during the coding process to identify connections to the research question. Concepts, themes, events and topical markers helped me to look at my data from different angles and identify influence.

3. "Frequently interrupt the coding to write a theoretical note" (Berg, 2009, p. 355).

This suggestion is a reminder that the theories help to guide the research. When a theme or concept arises, it is important to jot down ideas about the connection to the data as a theoretical note. While coding the interviews, when a connection arose between a theme or concept and critical disability theory or Sen's (1999) development theory, for example, I would make note of the connection and write down any thoughts or reminders

to make the connection in my research. For example, when participants would discuss inclusion in public schools, I would make a note on the connection to critical disability theory. This reminded me to bring all my analysis back to theory.

4. “Never assume the analytic relevance of any traditional variable such as age, sex, gender, social class, and so on until the data show it to be relevant” (Berg, 2009, p. 355).

This is important in the process of removing bias. When conducting my coding, I did not take the age, sex, gender or social class into account. I did separate the interviews into different categories based on connection to the Center: the parents’ and Kevin’s interview, then the staff and administration, then the NGOs’ and INGOs’ and then the government workers. Each of these categories gave insight to different aspects of the QOL framework and putting them together helped me to analyze and compare responses to various questions in order to see connections and themes.

After coding, I created a rich, thick description which, “has come to be used to refer to a highly descriptive, detailed presentation of the setting and in particular, the findings of the study” (Merriam, 2009, p. 227). Case study researchers use rich, thick descriptions to make transferability and generalizability statements to other potential settings. Transferability was a notion coined by Lincoln and Guba (1985) which stated, “the burden of proof lies less with the original investigator than with the person seeking to make the application elsewhere” (as cited in Merriam, 2005, p. 224). Merriam (2005) quoted Lincoln and Guba (1985) when she discussed the best way to ensure transferability is to create, “thick description of the sending context so that someone in a potential receiving context may assess the similarity between them and...the study” (p.

227). Through this rich, thick description, I make general statements about the lives of people with disabilities in Liberia and create a working hypothesis about what should be done to create a more inclusive environment in Liberia. Merriam (2009) cited Cronbach (1975) to define a working hypothesis when she stated that a working hypothesis, “...[that takes] account of local conditions can offer practitioners some guidance in making choices – the results of which can be monitored and evaluated in order to make better decisions in the future” (p. 225). The working hypotheses can be altered to adapt to a particular situation.

My thick, rich description consists of profiles of each student using direct quotations from family members interviewed and observations. Then, I created a five-point scale to determine influence with 0 being “not influential” and 4 being “extremely influential.” Table 5 describes each point in the scale of influence.

**Table 5: Scale of Influence**

Scale Rating	Description of Influence
0 -Not Influential	The participant did not refer to the domain or any part of the sub-domains. The participant stated that the Center did not influence his or her life in anyway. There was not an observation in the domain.
1 - Slightly Influential	The participant referred to the domain, but did not discuss the Center. There were a few observations in the domain.
2 - Somewhat Influential	The participant stated that the Center influenced his or her life or the student’s life, but did not give further explanation. There were some observations in the domain.
3 - Influential	The participant stated that the Center influenced his or her life and the life of the student and gave multiple examples. There were multiple observations in the domain per week.
4 - Extremely Influential	The participant stated that the Center changed his or her life drastically and his or her life or the life of the student is completely different under this domain. There were daily observations in the domain.

Using the numerical value given to each family under each domain based on their interviews responses, I determine the mean and standard deviation for each family. I also determine the mean and standard deviation for each domain. This adds to the discussion on the Center's level of influence across families and domains.

After determining the level of influence, I discuss the change in the students' and their families' lives. I connect the change back to critical disability theory, thus commenting on social issues surrounding the population of people with disabilities in Liberia and I bring in national data to place the lives of my participant in a setting or context.

### **Security and Confidentiality**

The data I collect is stored on a password-protected computer to which only I have access. In addition, the confidentiality of the participants is very important and I used pseudonyms for all participants. I gained informed consent from all participants, including primary caregivers for the participation of students.

### **Validity**

Qualitative research has certain characteristics in order to counter threats to internal and external validity and reliability. Merriam points out, “Regardless of the type of research, validity and reliability are concerns that can be approached through careful attention to a study’s conceptualization and the way in which the data are collected, analyzed, and interpreted, and the way in which the findings are presented” (p. 210). The reliability and validity of this study is determined through various suggestions from authors of qualitative research design (Berg, 2009; Creswell, 2007; Yin, 2009). This study triangulated the data by using participant observation, document review and interviews (semi-structured and unstructured). Many authors (see Berg, 2009; Creswell, 2007; Merriam, 2009; Yin, 2009) suggest using triangulation to ensure validity and reliability of data. Berg (2009) describes triangulation as, “multiple lines of sight” (p. 5) and states, “By combining several lines of sight, researchers obtain a better, more substantive picture of reality; a richer, more complete array of symbols and theoretical concepts; and a means of verifying these elements” (p. 5). These three strategies were tested against each other; i.e., the interviews can support or counter the documents and observation.

I considered my own bias when conducting qualitative research with regard to



internal validity and reliability. Creswell (2007) pointed out, “Qualitative research is a form of inquiry in which researchers make an interpretation of what they see, hear, and understand. The researchers’ interpretation cannot be separated from their own background, history, context, and prior understanding” (p. 39). In order to identify my own bias in the research, I conducted member checks, when possible. Merriam (2009) described member checks as, “The process... is to take your preliminary analysis back to some of the participants and ask whether your interpretation ‘rings true’” (p. 217). It was difficult to conduct member checks with some of the parents due to the lack of Internet access. Out of the 39 people interviewed, I was able to send emails to only 26 of the participants, either directly or through the director of the Center. I received a response from David stating the profiles of Adam and Zack were not skewed, and one of the development workers stating that I did not distort his words. One reason for this might be the lack of reliable Internet access for many of my participants and Liberia does not have a postal system, to my knowledge.

Conducting any type of qualitative research requires intense reflection into the researcher’s own bias, but researching a marginalized population, I feel, requires more. The researcher must remove himself or herself from the situation and simply comprehend what is going on beyond what he or she sees. This was an important component for me, even when developing my literature; I tried to be conscious of not saying things like this country *must* do this or that. It is not my place as a researcher to pass judgment or include my own bias in the research. It is difficult, if not nearly impossible, to remove all judgment and bias from research, but I have done my best to reflect, acknowledge my bias and remove it from any analysis.

Another validity strategy is prolonged engagement. I spent approximately four months in the field collecting data. “Prolonged engagement and persistent observation in the field include building trust with participants, learning the culture, and checking for misinformation that stems from distortions introduced by the researcher” (Creswell, 2007, p. 207). Trust building and learning culture is a very important strategy in teaching, as well. I taught students with disabilities for two years with the District of Columbia Public Schools. As a teacher, I had to gain the trust of my students and learn the cultural differences, as a majority of my students were African-American males from the East Coast and I am a Caucasian woman from the West Coast. I found that showing up every day and showing interest in their lives both inside and outside the classroom was important to developing a sense of trust. This strategy also worked in Liberia. I felt that I was able to gain the trust of the parents and students.

### **Chapter Summary**

Qualitative case study research provides a space to look deeply and on many levels. This chapter described the steps taken to create a complete picture of the lives of my participants. This study follows the outline and rules of case study research. This study has few questions of validity. It discussed ways to expose and remove my bias, along with a detailed outline of the steps taken to create a study that is reliable and valid.

## Chapter Five

### The Center, the Children and the Families: Finding Hope in Impossible Situations

The 2012-2013 school year began with 10 students, and one student, Mary, arrived late in October, bringing the total number of students to 11, all with varying disabilities from mild to severe.<sup>5</sup> The students arrive at approximately 8am and leave well into the evening, even though the Center's director, David, asks that students leave by 4:30pm. Most days begin with an opening prayer and song. The students are separated based on known cognitive ability, with those students perceived to be in grades one and two in the *upper*<sup>6</sup> class and those perceived to be in kindergarten or lower in the *lower* class. There is a 15 to 30 minute break about 10am and then lunch is served around 1pm. The students receive at least one meal a day and the meal regularly included meat or fish. On many days, a mid-morning snack is provided. The Center provides a slight sense of structure in the rather chaotic surrounding environment of the Red Light marketplace. Below is a table with a description of the student's gender, class, age, primary caretaker and impairment.

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<sup>5</sup> I only include 10 of the 11 students for reasons stated in the chapter on methodology.

<sup>6</sup> The Center uses the terms *upper* and *lower* class. These are not terms I would regularly choose to use due to the social hierarchically connotations.

**Table 6: Participants**

Name	Gender	Class	Age	Caretaker	Impairment	<b>Prof iles of the Stud ents : Upp er Clas</b>
Adam	Male	Upper	13	David and Praise	Cerebral Palsy	
Zack	Male	Upper	13	Father	Cerebral Palsy	
Patricia	Female	Upper	8	Uncle	Hearing	
Andrea	Female	Upper	13	Grandfather	Hearing	
Alexis	Female	Upper	6	Mother	Hearing	
Kevin	Male	Upper	15	Mother	Physical/epilepsy	
Joseph	Male	Lower	9	Mother	Unclear/Autism(?)	
Terri	Female	Lower	15	Mother	Epilepsy/Cognitive	
Denise	Female	Lower	13	Grandfather/Grandmother	Cognitive	
Mary	Female	Lower	8	Sister	Traumatic Brain Injury	

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Adam, Zack, Patricia, Alexis, Andrea and Kevin are students in the upper class.

This class is taught by two male teachers. One teacher, Andrew, teaches every day and the other, Joel, assists with teaching two days a week. The students learn ASL, basic math and writing. The class is taught on a regular basis and had one exam, which is in the appendix.

### **Adam**

Adam is the son of the director and lives at the school. I had one formal interview with both Adam's mother and father, but I spoke with them every day I volunteered at the Center. Adam lives with his parents, David and Praise, and his niece at the school.

Adam's sister visited often and I met his brother once, both older. Adam appeared to have positive relationships with all immediate family members. I interacted with Adam and his family the most, especially Adam's father, David, who quickly became my *go-to* person for cultural questions because of his candor. Adam is a very social person who could walk around the area near the school. Adam and Zack were best friends and they hung out on Saturdays playing football or watching a soccer match at the local video club.

Adam is approximately 13 years old. He is non-verbal and appears to have cerebral palsy. He has difficulty with fine motor skills, but is able to grasp a spoon and pencil with which to eat and write. He is unable close his mouth completely or control saliva. His parents attach a bib to his chest to catch the saliva. His arms have mild spasticity, but he has full command of his legs. He can sign the ASL alphabet, but has challenges with certain letters and uses one hand to hold down fingers. He appears to have relatively normal cognitive functioning. He can write his alphabet, as well as add and subtract most single-digit numbers. He understands commands and is able to execute basic tasks that are given to him, like getting a bowl, pencil, or using the restroom. A French physical therapist in the Ghanaian Refugee camp told David and Praise that Adams had cerebral palsy, but to this day, there has not been a medical diagnosis by a trained pediatrician, nor did Adam see a doctor on a regular basis for his disability.

**Emotional well-being.** Adam is a happy young man. He greeted me every day with a smile. He never started fights with the other children, but had a mischievous side, like many 13-year-old boys. One day, Joseph was playing with another student's feet; Adam walked up to Joseph and began putting his foot close to Joseph and then moving

away. Joseph seemed to enjoy playing this game and Adam often laughed during these moments. Adam was consistently happy during my volunteer work at the Center.

David believes that Adam loves the Center. David recounted a story where the teacher was telling the students that they needed to dress nicely for some upcoming festivities. Adam walked up to David and told him that, “[the Center] is for him” (personal communication, December 6, 2012). When I asked Adam if the Center was his, he smiled, nodded and pointed to himself. Adam’s took ownership of the Center. He worked hard most days. From my observations, he appeared eager to learn and was often the first one to the class when the teacher arrived.

The Center helps David cope with his own son’s disability because other children with disabilities surround him. He stated that the Center, “has helped me a lot...It has helped me to love my child more because I have seen the differences with all of them and whether I like it or not because God gave him to us...” (personal communication, December 6, 2012). Praise did not speak directly to her emotional well-being because of the Center; however, her interactions with the students were motherly. She helped the children and cared for them when any one of them was upset. She laughed and smiled a lot. One day, she called me into the lower class and asked me to listen to a student recite the alphabet. She stated that she had worked with the student for a full year to learn the alphabet and was proud that the student could recite it for me (personal communication, October 3, 2012).

**Inter-personal relations.** Adam does not appear to have any problems with his relationship in his family or the immediate community because of his disability. Praise

did recount a few stories of people in the community disrespecting Adam by giving him foul food or yelling at him because of his saliva. In both instances, Praise spoke to the women and stated that Adam did not have any more problems with them (personal communication, December 12, 2012). Children in the community were willing to interact with Adam when he had a soccer ball. David stated, “[Adam] does have some friends that come and play with him, like for his football. As long as [Adam] has a football, they will come around and they will play with him” (personal communication, December 6, 2012). David continued that children from the community will only play with Adam when he has a soccer ball because, “The children are afraid that maybe the drool will touch them, something like that, so we always encourage to wipe his mouth” (personal communication, December 6, 2012). Adam (and Zack) enjoys free membership to the local video club. Praise said that Adam is an honorary member for life because he helped to build it (personal communication, October 20, 2012). Adam appears comfortable walking around the community. Praise and David had regular relations with the community, as well.

David and Praise stated that Adam is accepted and loved by all his family members. Praise remarked, “...whenever he is sitting they [his brother and sister] would take his copybook and his pencil and they hold his hands and they try to write” (personal communication, December 12, 2012). When asked why their family appears to be so different from many other families with children with disabilities, Praise responded, “...they saw [Adam] from the initial stage when he was born. They know he was not born like this. They are thinking, what really happened? They love [Adam] because they have love for me” (personal communication, December 12, 2012). David and Praise’s

comments were corroborated by positive interactions observed between Adam, his siblings and his niece. Adam was not treated differently from the rest of the family and appeared to be cared for just as much.

**Material well-being.** David and Praise understood the realities of having a disability in Liberia and his mother was confident he would always have help. She stated, “I believe that in future, he will be ok and if he doesn’t have a job, his sister and his brother will be able to help him” (personal communication, December 12, 2012). When asked about a job for Adam, David spoke more to his hopes for the future of the Center in order to help Adam get a job. He stated,

For [Adam], if he can get a job...we would be happy and for [the Center], we are looking at the basic education stuff, but we are seeing if some vocational stuff can be brought in...we decided we would make this place like a starter pack, we bring them in and give them basic education and then they would be transferred to a regular school, but since the government is trying to do this inclusion, we would like to have [the Center] transformed to have both kinds of children...sit in one class. We also plan to go beyond the age range we have, like from age 2 to 17, we are hoping to have [the Center] go to high school level...we want to include some vocational education. (personal communication, December 12, 2012)

Adam’s parents are hopeful that he will find a job, but Praise is very realistic and understands that Adam may have to rely on his brother and sister for help.

**Personal development.** David and Praise stated that they treat Adam the same as their other children (personal communication, December 6 and 12, 2012, respectively).



They taught Adam to help with things around the house. Praise stated, "...[Adam], he hears and he do things like the normal children, sometimes he draws water into the drum and he fixes water to take his bath, but some of the children [at the Center]..., they don't really do it..." (personal communication, December 12, 2012). David continued:

There are some things that a normal person may do, like for washing clothes, he wants to begin washing his clothes, but because the left hand is not as good as the right, so we don't allow him to wash clothes, but he takes his bath with the right hand, he washes dishes and he sweeps...like this Sunday, he asked me for the key [to the water pump], he filled up the barrel, he washed the dishes, he helped his mother to put the coal into the coal pot and Sunday, he was on, he was willing to do any work without someone telling him...but sometimes, when he is not willing to work, you can't get him to do anything, so sometimes, he is stubborn....

(personal communication, December 6, 2012)

Adam also learns a lot as a student at the Center. The class test showed that he understands basic addition and subtractions (see appendix). He is able to sign the alphabet and knew many vocabulary words in ASL. It was unclear if Adam knew how to read, but he can identify letters.

**Physical well-being.** Adam's parents worried about Adam wandering off to places that might be dangerous for any Liberian, like large main roads. David stated,

During the rainy season, we have a lot of swamps around and the fear is that he doesn't know how to swim. Fear is also that he could be led by [Zack] or maybe someone to go one direction. He is not used to the bike riders and until he gets to

one side, they could knock him down. (personal communication, December 6, 2012)

David felt comfortable in the community and believed that Adam was safe. He stated,

This community is better off... It doesn't have gangsters or lots of criminals.

Adam is safe. Maybe because of his drooling, when he gets into public, they may not want to stand near him because they have fear of the drool getting on them.

His mother may not have that confidence for Adam to get out there, [but] he is safe. For her as a mother, she has always over-protected her children, but for me, I like for them to experience life for themselves. (personal communication, December 6, 2012)

There were a few occasions when I went to the Center on Saturday. Adam and Zack were at a local video club and playing soccer. David and Praise seemed at ease with him in those places. There was one instance when someone came and told Praise that Adam and Zack went to the main road. Praise became very upset and concerned for Adam and Zack's safety because of cars and motorbikes.

**Self-determination.** Adam is able to make his own decisions. His parents allow Adam to purchase his own food, snacks or sometimes items for the family. David stated,

The moment you give him 10 dollars he goes right down and he buys a friend chicken to come and eat it. When he is out there, people that he knows will give him the money and once they give him the money he goes and buys his fish or his chicken or his boiled egg and he brings it to put on his boiled rice to eat. He is able to know the difference between a five and 10, but not a 20 or 25. Even if you

are sending him to buy a bag of coal. You tell him that you are giving him 20, when you go tell them that you want a big bag of coal. They give him a big plastic. (personal communication, December 6, 2012)

Praise stated that she must tell Adam that she is giving him a 20 Liberian dollar bill and the exact size coal bag she would like him to purchase. Adam understands the difference between small bills, such as five and 10, but has difficulty recognizing larger bills, such as 20's.

**Social inclusion.** David and Praise create an inclusive environment for Adam, as much as possible. They do not exclude him from family functions, and they stated that family members accept Adam. However, within the community, Adam faces some discrimination. Praise recounted this story of a time when she had to stick up for Adam when he tried to buy a piece of chicken,

...The woman give [Adam] the chicken that slept [was from the previous night] and then she brought it back to sell, so when she give to [Adam], [Adam] brought it to me so when I look at it, I say this chicken is not good. I went back to her and say, 'are you the one that sold this chicken,' she said 'yes,' I said 'look at this particular thing, can your children eat it?' She said, 'Oh, sorry.' So that now she said she would fix a new one to give to [Adam], I said 'no, just give me the money.' (personal communication, December 12, 2012)

When they lived in the refugee camp in Ghana, David noticed that children with disabilities were not included and Adam did not have a school. He decided to start a Center for his son with a few other parents who were concerned for their children with

disabilities. Upon returning from the refugee camp in Ghana, David knew Adam would still be excluded from most of society. He recalled his thoughts,

... [I thought] if I have to come home, where will [Adam] fit? Because knowing that our society has not begun to accept these kind of children and teachers may not be available or teachers may not have the patience. I thought that if I come home, where can I get help or how can I start? (personal communication, December 6, 2012)

The Center helped to raise awareness about children with disabilities by simply being open. For Adam, his parents work to create a more inclusive environment for him within the community by discussing disability with neighbors, running a center for children with disabilities and not hiding their son in the house.

**Rights.** David and Praise were the only two parents I interviewed that could elaborate on why inclusion would be best for their child and who desired an inclusive society. David said,

There should be. I would like inclusion. One reason is so that the normal students will be able to understand these disabled children to know their problem, they will sit in the same class. There will be that love and friendship between the both groups and two it will help to reduce that stigma from the classroom from the adults too because once these kids don't sit with the disabled children that love won't be there for these children so they won't have that much care for them. That too will also help to make that communication easier between the both groups. These children who are regular could be taught the sign language too. They could

be assigned as interpreters around the country. That will help them to earn some money... If we don't do it, there won't be totally love between these two societies... (personal communication, December 6, 2012)

Praise discussed very specific things that she felt would help people with disabilities and Adam in the future. She stated, "they need money, housing, a place where the children with disability will be and people will be there catering to them...in the community, so that the community member can get adjusted to them" (personal communication, December 12, 2012).

Praise also recounted a story regarding her work as a volunteer at a polling booth during the most recent election,

...during our election, I was serving as one of the observers and the disabled went to vote, even those that couldn't walk. They didn't go on line, they told the able body people to go aside for the people who have problem to give them to vote. They were like special on that day, they had the right. (personal communication, December 12, 2012)

Praise and David are the most educated at the Center on disability rights. Their interviews showed that they wanted rights for their child. Nevertheless, it appears people with disabilities are only special on voting days. There was no discussion on empowering people with disabilities in Praise's interview. David did mention the need to reduce stigma and increase love. He also recognized the need to bridge the gap between the two societies, those with disabilities and those without, which is a rare observation among my participants.

## **Zack**

I was able to interview Zack's father and visit him at his workplace. I passed Zack's house on the way to other home visits, but did not conduct a home visit. Zack is 13 years old and has been a student at the Center since 2009. Zack has a brother and a sister who attend government schools. Zack is often home alone because his parents work. Zack also wanders the community. He greets all visitors to the Center with a smile and handshake. The director of Special Education said, "[Zack] has a charm beyond belief" (personal communication, November 27, 2012). Although Zack's father is a carpenter, his family seems to be the most economically disadvantaged in the school. His house is made of corrugated zinc and he often spends his weekends at the school or a local video club where he enjoys free membership. On many occasions, students would buy Zack sweets or snacks from the local vendors. David hired Zack's father to complete the Center's desks, even though David's family chastised him for giving work to someone outside the family.

Zack was the first student to begin attending the Center. David found him wandering the community, discovered where he lived, and spoke to his parents about the potential for a center for children with disabilities (personal communication, December 6, 2012). Zack appears to have cerebral palsy. He has problems walking because his knees fall in, knocking together as he walks. He has difficulty with dexterity and fine motor skills. He appears to have dyslexia and dyscalculia.

**Emotional well-being.** At the Center, I observed Zack acting as I would expect a 13-year-old to act. He was studious in class, hurt when another student took something from him, and he would instigate bad behavior in other students when it suited his need

for entertainment. For example, another student was lying on the floor wrapping his feet around the feet of those sitting on the bench and attempting to pull the person to the ground in order to wrestle. Zack was sitting on the opposite bench. When the student attempted to wrap his legs around Zack, he began to laugh and wrestled with the student on the ground. This is an example of Zack's comfort at the Center and playful attitude toward the other students.

It is clear from Zack's demeanor at the Center that he is happy to be there. His father said,

Before [the Center], he was just going [anywhere around the community]... I don't sit at home. [His] mother don't sit at home. He just go up and down, roams the community. I was not happy of it. I can't help. [Now, Zack], you take [Zack] to hospital clean the ear, when [Zack] clean the ear, he was happy. OK... happy... what so ever they do here, he is happy. Yesterday, they give him I.D. card. He take it and show it to me. He was happy. ... I am happy of it. I can see he not sad, when he go home he show to read, to write, to sign something. He tell me happily. (personal communication, October 24, 2012)

At home, his father recounted many stories about the stubbornness and successes he faces when attempting to raise a teenager with a disability:

...sometimes when you tell him [to bath]. When you want to bath him, he won't allow it. He want to bath himself. In the morning, scrub his mouth. He stubborn for it.

He continues by describing some helpful things Zack does around the house,

[Zack], when he see me, I doing something [and] he like to help do it, but now he not able. If I eating, he bring water. I finish, he take the dishes...[and] clean the dishes. (personal communication, October 24, 2012)

Zack's disability inhibits his ability to do things, such as help his father around the house. Zack has difficulty grasping items, walking and standing due to his disability.

Zack's emotional well-being appears to have improved after entering the program at the Center based on his father's interview and my observations at the Center. From observations, Zack seems comfortable with the staff and the other students. He smiles and laughs a lot. He is eager to meet anyone at the door for a handshake.

**Inter-personal relations.** There are some people in the community, including some of his extended family, that do not allow Zack around their house because of his disability:

... there some adults that know how to treat [Zack] bad...They only make fun of [Zack]. [Zack] best friend only here, [Adam], because [Adam] go look for [Zack]. I get a big brother over there, but his children don't call [Zack] anything. They don't like [Zack]. They see [Zack]. They make fun of [Zack], so I don't let [Zack] visit there. Me, I can visit there all the time, I get job. I can visit there. [Zack] can only go here. (personal communication, October 24, 2012)

Although Zack's treatment by the community and his extended family is a common story for students at the Center, Zack's father's story of the treatment of Zack by the community seems to be one of the worst. Zack's father is very happy that he is able to attend the Center because of the ill treatment his son faces in the community. "I will be



angry from it. The most thing I am happy that he can spend the day here” (personal communication, October 24, 2012).

Communities ostracize people with disabilities. This makes creating relationships, including friendships, difficult. Zack is lucky because the Center has created a space where children with disabilities are able to develop friendships that might not have otherwise been established in the community.

**Material well-being.** Zack’s father has hopes that his son will learn a trade or be able to obtain some type of employment. He stated,

Well, I just hoping, in the name of Allah, for [Zack] to better, as the way you people are like this, that he can learn something in the future for better future for him and for myself. Any trade that he able to pick up in that condition that he in. (personal communication, October 24, 2012)

He has a strong trust in the education Zack is obtaining at the Center. He said,

...this school here, I believe that it can help [Zack] just be somebody. I love [Zack] enter here. I have that belief that [Zack] will be somebody, if you people are help because if not you people, [Zack] will remain like that because no help. I believe [Zack] must stay here until he can become somebody. (personal communication, October 24, 2012)

Zack’s father is not entirely sure what will happen to Zack in the future, but it is clear that the Center has aided in his father’s conviction that Zack could get a job other than be a beggar in the future. Zack has shown improvement and retention of knowledge learned

in class. The teacher at the Center has helped Zack to learn some ASL to help Zack communicate with those that know ASL. It is unclear how (or if) these skills will translate into a career.

**Personal development.** Although Zack's future is unknown, Zack's father is extremely happy with the Center and the skills Zack is gaining.

[Zack] is learning, here now, he can write, he go and tell me, he can write, he not do that before, when he sit down he singing, he can sing here, he not used to do that before. Now when [Zack] go home, he take the copybook and he write, I be sitting down and watching him, he write, before he take his uniform off, he be writing. Now when his big brother come and take the copybook and do, so, so. Anyway, he improving small, small. (Personal communication, October 24, 2012)

David also told a story about the end-of-year program:

When [Zack] came here, [Zack] was writing everything backwards. Last year, in June [2012], when [Zack] was called on the blackboard to write and he wrote from A – H, so the community members who were at the program saw that, we saw surprises on their faces. We heard them saying, “oh, he's able to learn, Oh, he's able to write, I did not know. I did not think.” (personal communication, December 6, 2012)

Zack has learned the alphabet, numbers and addition because of his attendance at the Center. The Center has influenced Zack's personal development, and his father has a better understanding of Zack's abilities. Zack's father seemed impressed with his son's

improvement at the Center and David and Praise spoke highly of Zack's changes from his first time at the Center to now.

**Physical well-being.** As mentioned earlier, Zack has difficulty walking and it appears to be painful to walk too far away from his home or school. After receiving his hearing aids, David, Paula, a few students and I walked around to each house to teach the parents how to use the hearing aids. Zack's father's workshop was the first stop because he was unable to make the entire trip around the community. We also had to stop several times for Zack to rest his legs. When he reached his father's workshop, we had to cross a small stream via a fallen log. Zack's father was on one side and David was on the other attempting to help Zack across the log. Luckily, he made it without falling, but his father and David had a hand on him the entire time because of the unstable *bridge*. The terrain of the local community is difficult for Zack to navigate due to his disability.

Zack's father believes that Zack's disability is a medical issue and has consulted with many different people to explore options for Zack.

I believe it was medical, but there is no name to undertake...[Zack]'s mother told me that she was pregnant with [Zack], she fell. When [Zack] was a child to sit down 3 months, he couldn't sit down straight. What I used to do, find some leaves, warming, warming, until God could help me, he start walking. That's the one I was doing to make him walk like that because I not make the monies for hospital because you go to hospital, you don't get money, nobody look at you. One Bassa lady, I went to her, I said, my son can't walk, she say ok, when I carry him, she check and I carry [Zack] back here. She said [Zack] got problem, she

said the bone is not sitting good, That is the time that the mother told the lady that she fell down. She said that we must get some leaves...to get warming [Zack] and that will make him strong. (personal communication, October 24, 2012)

Zack's father and mother took Zack to an herbalist. The herbalist suggested that Zack's parents collect a specific type of leaf and burn the leaves to help Zack learn to walk. It is unclear the type of leaf. I am also not sure what was done with the leaves after they were burned; perhaps, the leaves were just burned and the smoke was used to "heal" Zack or there was something else Zack's father did with the leaves.

None of the doctors Zack visited suggested it was cerebral palsy or a cognitive disorder. At first, Zack's father thought his son had a *tied tongue*. He stated,

...people say that [Zack] have tied tongue...so mother used to take [Zack] to hospital to cut under the tongue, but I think it don't work, so [Zack] couldn't talk and [Zack] couldn't walk. [Zack] just sat down for 4 years, he just sat down, he can't walk...Then for [Zack] to walk, I took him to one doctor, he said that the spinal cord it not sit down good. At that time, I didn't have money to take him somewhere. He said that if [Zack] walk, his foot would not be straight and that is what I am thinking, what I know about [Zack]. When he was child, I play with [Zack] and I check in the ear, when I check in the ear, I saw something inside the ear and I take a cotton ball inside the ear and it was STRONG, so I found a little pin and try and pick it out, but I was scared to not go inside, but it move, but sometimes it look like it still there, sometimes it can grow back. That is what I notice about it. (personal communication, October 24, 2012)

Zack's father is referring to wax and dirt in Zack's ear. When Zack went to see the people from the Starkey Hearing Foundation, the ear care specialist cleaned Zack's ears and commented that he had a lot of wax and dirt build up, which could account for his partial hearing loss.

Zack has had safety problems in the community in the past. His father recounted these stories:

One time, [Zack] had a stick [a cane to help him walk]; they took it from [Zack]. I don't see the person that took it. The slippers [shoes], they took it from him.

When I get there, I don't know who took it. I feel bad about those things. That why sometimes we can buy one slipper [shoes] for him, it can be ugly, but we are still use it because then some people will not take it from him. (personal communication, October 24, 2012)

Home safety, in terms of family abuse, does not appear to be a concern. Zack's father is active in his life and attended the parent/teacher association meeting. He stated, "I treat [Zack] well than the other children, I get feeling for [Zack], because of disability, I get feeling for him for that, he my lovely child. I look up to God" (personal communication, October 24, 2012). Zack is still beat on when his father gets *vexed*, but there were few parents that said that they do not beat their children. When investigated further, Zack's father said he used his hand and it was usually on the backside, more like a spanking than a beating (personal communication, October 24, 2012).

Zack is able to help around the house, but his mother forbids him from being in the kitchen for fear that he will fall. His father stated, "He like to do it, he like to sweep,

sometime he fall down. When the woman is cooking, she says no, he fall down. That's only thing. He like to do it" (personal communication, October 24, 2012). There is a sense of pity for many of the students at the Center and Zack's father *feels bad* for his son's disability, but has not been advised on the things his son will be able to do in the future due to the lack (and expense) of medical care available to most Liberians.

The Center has not provided information on Zack's disability to his father, but his father is grateful that there are people around to help his son learn and the Center has helped Zack's father recognize the strengths his son possesses. The Center also provides a safe space for Zack in a community that has abused him in the past.

**Self-determination.** According to David and Praise, Zack wanders the community a lot and comes to the Center on the weekends to hang out with Adam. Zack is able to make choices based on how he spends his day.

**Social inclusion.** As stated earlier, Zack is not socially included in the local community. However, the Center has made strides to help the community accept Zack through the end of the year program and various conversations among the staff members and the local population. The Center is a micro-community that has created a space where Zack is socially accepted, he has friends and his father has become more accepting of Zack's disability.

Many schools in Liberia have a king and queen ceremony during the anniversary celebration. The Center's celebration was December 16, 2012 and they chose a new queen and king. There are boxes placed in front of each candidate and money is placed in the boxes for various rounds. The candidate with the most money wins the crown. Zack

won the crown for the 2012 – 2013 school year. This is an example of Zack's increased community acceptance because of the Center.

**Rights.** Zack's father was very excited about finding the Center because of the prior lack of opportunities available for students with disabilities in Liberia. He stated,

My first when I hear about it... about three years now. As soon I hear about it, they take [Zack] from me and they bring him here and since that time, I thank God that they are doing well for [Zack]. I am happy with it. I was very worried about [Zack] because I don't have financial to sponsor [Zack] in school and I was thinking, 'what school or who I can find to take [Zack] to have a disability?', to the Catholics, I took [Zack] there [to a Catholic boarding school for children with disabilities] and they say no and I say why and they say because [Zack] can't speak and then the other one to rehab and I took [Zack] there and I put him on my back and they say no, there is no chance. (personal communication, October 24, 2012)

The Center was Zack's only option. Other schools for children with disabilities turned Zack away because he has a severe speech impairment. Later in the conversation, Zack's father expressed his concern for the lack of facilities for people with disabilities and the government indifference to the plight of his son. He stated,

It be difficult because here you not get money, people not help you, yes, because the children say they alright, you go to government school, you can face problem with that, they come a lot of complainant for this and that and money for this and that and [Zack] is disabled, he go to government school, they not allow him

inside. They will not allow him. Even government school, we don't have disabled government school. Only people, NGO, start helping the disability school. Here, government don't do it. Brother and sister attend government school and I don't think they will allow [Zack] to attend it because I not see it yet. No, because I have not seen any disability attending government school. You people are taking care of [Zack], when [Zack] get big like this will he continue to come here, if you all will take care of [Zack] until he get to high school or able to get him to college. I hope for that. (personal communication, October 24, 2012)

Although the Center has not directly worked with the government to increase the rights of children with disabilities, the educational opportunities offered to children in the community has helped to raise awareness about the need for rights. For Zack's father, it appears that the Center has helped him to raise his expectations for his son.

### **Patricia**

I conducted two formal interviews with Patricia's uncle, the primary caregiver, and interacted with him, as he regularly visited the school and attended all school events. One interview was at the Center and the other was a home visit. I also met Patricia's mother. Patricia's mother called me on several occasions for various reasons. She also stopped by the Center on two occasions while I was there, once was to introduce herself and ask if I could take Patricia to the United States with me and the second time was when she asked my medical opinion.

Patricia is an 8-year-old girl who started coming to the Center at the beginning of the 2012-2013 school year. She has a hearing and speech impairment. Patricia's best



friend at the Center is Andrea. They both enjoy playing hopscotch on the front porch and Patricia has some skills on the double Dutch jump ropes as well. She does have a temper and did get into a few screaming, crying, and hitting matches with some of the students over food and money. Patricia brought her own food to school every day and would share it with some of the students depending on her mood. She also brought money that sometimes disappeared and then she would blame a student, sometimes justifiably, sometimes not. Patricia's mood swings appeared normal for an 8-year-old.

Patricia's mother travels a lot for work and her father lives in South Korea. It is unclear how often he visits. Patricia lives with her uncle and his wife in another area of Red Light. Patricia's uncle drives a "pen-pen," a motorcycle taxi. They live in a single story building of one-room apartments. The room has a mattress on the floor, a table, piles of clothes and a small TV. The kitchen has a coal-burning stove just outside the front door. There was a wire cord, used for drying clothes, attached between the front door and the front building. Patricia seemed well taken care of by her uncle. She appears to enjoy the school and her uncle is supportive in helping Patricia get an education.

**Emotional well-being.** Patricia appears to be a happy 8-year-old. Patricia's uncle is very pleased with the programming at the Center and believes that Patricia enjoys her time at the Center (personal communication, October 26, 2012). She laughs and plays with the other children. She sometimes bullies the other kids when playing hopscotch or jump rope. She tells other students they are not allowed to play the game or will yell if someone strays slightly from the rules. Patricia appears to have a strong personality. She will tell you when she is angry, happy or sad about an event. Although she has challenges vocalizing words, she can communicate well.

Patricia's uncle is a religious person and copes with the difficulties of Patricia's disability through his religion. He stated, "It can be hard sometimes. Through God, I understand, because sometimes she can hear some. So when I say something, I can make sign before she can go for the other one" (personal communication, October 26, 2012). Religion plays a role in many Liberians' lives. Patricia's uncle seeks guidance through his God to understand life events.

**Inter-personal relations.** It was unclear regarding the relationship between Patricia and her mother. Her mother came to the Center a few times very concerned about Patricia, but it appeared she was more concerned because I was a White person. She asked me on several occasions to pay for Patricia to go to the United States or to pay for Patricia to go to a private school. Patricia's uncle told me on many occasions that the relationship between Patricia and her mother was not good because her mother yells a lot and Patricia is not used to that because he does not yell or get upset. He stated,

Mostly, her mother, not that friendly, she can only be friendly for a minute because her mother, she is someone that is shouting at children and... [Patricia] don't love it because she not grew up with it. When I say go inside, it's just go inside. I don't gotta shout it... (personal communication, October 26, 2012)

Patricia's relationship with her community is good. Patricia has five girlfriends and her uncle told me that they understand each other very well, even though the girls are all hearing (personal communication, October 26, 2012). He said, "They can understand each other because Patricia is showing them, so they know it. They know more than me" (personal communication, October 26, 2012). She visits their homes, but does not wander

the community. Patricia's uncle believes that if she wanders the community, "they [the community] will think I am bad person, so based on this, I keep her home" (personal communication, October 26, 2012). Patricia is not kept in the house all the time. She is just not allowed to wander the community.

People in Patricia's community and at the Center like her, but she does have a temper. There were many occasions when Patricia would argue with the other students. The students understood each other, so the communication difficulties were not as high as in the community. The uncle complemented this observation by speaking about Patricia's difficulties in the community, "When you do anything to her and when she come to me to complain, I will not do anything, I will only say sorry" (personal communication, October 26, 2012). Her uncle believes that because she understands that he will not do anything physical to the other person she tends to take matters into her own hands (personal communication, October 26, 2012).

From observations and conversations with other Liberians, Patricia seems to have a normal weekend life. On Saturday, many Liberians will wash clothes, clean and go to the market. Patricia's uncle works on Saturdays, so she stays with her aunts. He said,

Saturday...mostly I can go to work. I put clothes out for washing, her underclothes, so she can learn how to wash. Then she find her Aunties and she go to the market to buy food and come with Auntie to cook and eat. (personal communication, October 25, 2012).

Most of the stress from his relationship with Patricia stems from communication conflicts, which was a common thread with all the parents. The uncle stated, "Most of the

difficulties is just because of the hearing...sometimes you can yell at her, she can be sitting there and you calling her and it can be a year before she can turn around” (personal communication, October 26, 2012). The Center’s ASL program has helped Patricia communicate better with friends and family, which could have an effect on her ability to develop inter-personal relationships, but I did not observe how the Center furthered her inter-personal relationships. Her uncle was already very active in her life and spent a lot of time and energy on Patricia, which will be further explored in other sections. She is an outgoing young girl and was easily able to develop her own relationships in the community without the help of the Center.

**Material well-being.** Patricia’s future financial security is unclear. As discussed earlier, people with hearing impairments are not likely to obtain reliable employment without increased intervention. As with other parents, the future is vague and Patricia’s uncle just hoped that things would be better for her. When asked which skills and training he would like the Center to focus on, he stated,

Most days, I want you people to help how best to take care of things because tomorrow I may not be around. Tomorrow she may be able to do those things for her very self... To prepare food for herself, to buy other things for her very self and when she grows up maybe she saves some money for me. (personal communication, October 26, 2012)

Liberian parents expect their children to take care of them when they are older (personal communication, December 8, 2012), but a child with a disability will have a harder time because of the lack of services, and discrimination in the job market. Patricia’s uncle

pointed out that some of the discrimination stems from this desire to be taken care of when one is older and the lack of understanding that people with disabilities can become capable adults. He stated,

Mostly they [Liberians in general] do not treat them good because they say, why am I wasting my time, so, they will not highly cater to them. Some of them will say, if I do this, what will you [person with a disability] do for me. Nothing. Only few people, which will cater to these people. (personal communication, October 26, 2012)

This was a common theme in many of the conversations with parents and other participants. Her uncle understands the difficulties of raising a child with a disability in Liberia and sees education as the path to help Patricia retain employment. He said,

What she can do tomorrow is what she can learn today and maybe she be able to do something tomorrow. If she not do anything, she not do anything. Like you, once upon a time, you like something and now that brought you here today, so if she not learn anything today, tomorrow, she will not be with us, I don't know what will become of her. (personal communication, October 26, 2012)

Patricia appears properly fed and she is the only student that brought food on a daily basis to the school. Her uncle commented that she would eat anything with meat. He stated, "She not like dry rice. She loves, mostly, meat" (personal communication, October 26, 2012). David confirmed this by stating that Patricia will walk in the kitchen and ask for meat if there is not any on her plate (personal communication, October 26, 2012). If there is not meat in the meal, she will likely not eat it. David also told me that in

Liberian culture, meat is a sign of wealth, so when a family does not have meat in their kitchen, the community might look down upon them.

**Personal development.** The Center focuses mostly on education. Many of the parents, including Patricia's uncle, have seen gains in education. Please see the appendix to see evidence of her work. He stated,

[Patricia], I have seen some great changes, mostly, her education line is improving... Sometimes when she come tell me that she write and she can show me what to write, like her name, when she get her assignment, she can write it down. So based on that because what they are teaching here, the other school on the other side, I can see the children, because I can compare the note and it's the same thing. It's gradually improving. (personal communication, October 26, 2012)

Before coming to the Center, Patricia knew how to write. Her uncle recounted her morning routine, "In the morning, I can fix her breakfast, she take the water to take bath and then I put a show on, I take the copybook and I take the bible, that my only book" (personal communication, 26 October 2012). Her uncle worked very hard to teach Patricia how to write. Upon entering the Center, Patricia had a good foundation for copying, but ASL and math has helped to increase Patricia's literacy and numeracy (Please see the attached tests for examples).

Her uncle has also seen some development in her personal hygiene because of the Center. When asked about improvements she made since attending the Center, he stated, "The ability to writing and cleanliness. Sometime after school, she take off her uniform

and...before you eat, wash your hands. In the morning hours, daybreak, teeth brush...It was here [the Center] that she is mostly picking it up” (personal communication, October 26, 2012). All students are required to wash their hands before eating and after using the toilet.

Patricia’s uncle would like to be able to teach her societal norms and relay basic moral ideas to Patricia, but because no one in the family, including Patricia, has had the opportunity to learn any sign language, he has not been able to. When asked what difficulties he faces with Patricia, he responded,

Mostly, how best to come on in society, so based on this, because she is with me, because once upon a time I was with my father and he brought me up this way and I want her to come up that same way. Based on the hearing, that’s how some of the difficulties that is giving hard times. (personal communication, October 26, 2012)

According to Patricia’s uncle, the Center helps her develop more skills than he was able to provide. He stated that he had not tried to send her to another school because she has a hearing impairment.

In the few months that Patricia has attended the Center, she has learned various ASL vocabulary words, the ASL alphabet, increased her math and writing skills and made friends. The Center has influenced Patricia’s personal development and her uncle feels that it has made a positive impact on her life.

**Physical well-being.** Patricia is the only student, to my knowledge, to have traveled for the purpose of medical care. When Patricia was much younger, her family took her to Egypt.

They went to the hospital and they told her that [Patricia] have the tied tongue, so at the time that mother was very sick, so the older sister, they took [Patricia] and carried her to Egypt for the same problem... they take her to Egypt and do the ear washing and certain measurement that they make for the ear [to provide a hearing aid], but she doesn't want to use it. (personal communication, October 26, 2012)

She received a hearing aid in Egypt, but she does not wear it because she does not like it. Patricia was a recipient of a hearing aid from the Starkey Hearing Foundation. It seemed to fit better, but like most of the students, she would turn them off because of the sound overload.

Patricia's mother called the uncle frantically one day and stated that she had found a *cure* for her daughter (personal communication, November 18, 2012). According to Patricia's uncle, the doctor had been walking around the community looking for patients and his wife told him about Patricia's disability (personal communication, November 24, 2012). A doctor convinced Patricia's mother that her daughter had a *tied tongue*. A small incision was made under Patricia's tongue. The doctor told the uncle this was to help the tongue move more freely so Patricia could form words. The doctor did not believe that Patricia was hard of hearing and attributed Patricia's non-verbal disability to her tongue. The doctor stated, "She is not bobo, she can talk. Bobo people can't talk"



(personal communication, November 20, 2012).<sup>7</sup> For Patricia's mother, there is not a spectrum of hearing loss; either she hears or she does not. Patricia can hear a little bit if you are close, facing her and speak loudly. Her verbal abilities are very low, but she understands some things. David asked me not to take sides with either the mother or the uncle. David does not want the Center to gain any bad press in the community by telling parents what to do or what not to do with their children. He is afraid that parents will begin removing the children from the Center and bring potential harm to those that are at the Center. This is an example of the Center's precarious balance between what might be best for the child and the politics of disability in Liberia.

Without the availability of proper medical consultations, many parents are forced to consult with doctors that roam the community, unable to confirm knowledge of the doctor's background. Patricia's uncle does not believe that the procedure was effective and feels that the hearing aid donated by Starkey International has helped Patricia. When I asked if he saw any difference in Patricia's verbal abilities after the hearing aid and the procedure, he stated, "The only difference which I see is that her way of say papa and mama... but I think that the hearing aid is helping them to talk bit by bit" (personal communication, November 24, 2012). The Center is not equipped to help students with medical decisions. There is no physician or trained medical professional on staff. Patricia is safe at the Center, but the Center has not done trainings to explain the various disabilities because of lack of funding and trained personal.

**Self-determination.** Patricia's hearing loss limits her ability to make decisions and have the same autonomy that other 8-year-olds have in Liberia. Her uncle said,

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<sup>7</sup> *Bobo* is a term used to describe people that cannot talk.

Like at home, other children, you can send them to go buy things in the community... I don't know the sign, because if I call the name and I don't know the name in sign, how will I know, so I try to put a stop to it. Communication is very difficult, so, based on this, I know what she wants I can go and she can put a finger on it and she can buy it... Mostly, I give her money to buy orange. She can go by herself. (personal communication, October 26, 2012)

**Social inclusion.** Patricia appears to be accepted in her community, but is not socially included in the greater society. Like many of the students, there are unanswered questions about her ability to retain employment because of her disability. The Center has done limited community awareness, except through private discussion and school celebrations.

Her uncle has not tried to place her in the public school because of her hearing impairment. When asked if students with disabilities should be included in the general population, he stated:

They can't be with everybody, the hearing business, the sound is difficult, when the teacher is teaching on the blackboard, it will give them hard time, for them to ask the questions it would be hard, I believe that they can ask questions through the sign. Sitting with them, there is no problem with that, the problem is, the hearing, the communication side... Yea, those people, I believe that the people have the teachers for them, so if those people are there and they have the instructor for them to teach them, then I believe there is no need, they can sit together and teach them, but if, like here [at the Center] now, those that can teach

the blind, nobody here is an instructor which can teach blind person, even if a blind man come here, what will be the learning process for him, so there is no need for them to be here, except at the school where the blind instructor can teach them to help them very self. (personal communication, October 26, 2012)

**Rights.** She does not receive any government-sponsored support and this is Patricia's first school. When asked if Patricia had the same opportunities as other children, the uncle stated, "No, because the Liberia government is not interested in all that one there. They don't have interest" (personal communication, October 26, 2012). The Center offers basic education to students who would otherwise not be afforded one.

### **Andrea**

I interviewed Andrea's grandfather twice. One time at the Center and the second time on a home visit. Andrea's grandfather participated in the parent/teacher association meeting. Andrea lives with her grandfather and other family members in a concrete building near a mosque and tailoring center in Red Light, very close to the school. Andrea spent her first years of schooling in the interior area of Liberia. This is Andrea's first year at the Center. Her grandfather said that the family actually moved to Monrovia at the suggestion of Andrea's school in the interior.

...it was from there [the interior school], that the teacher was observing that this girl would be somebody in future. So she need to come into town to see whether we can find a deaf and blind school that where she can go to start doing something. Maybe her life will improve more than this [life in the interior]. (personal communication, November 6, 2012)

The grandfather found the Center and moved to Monrovia. He stated, "...life was not improving there. She can't understand the teaching condition...just through God, we can find this area through friendship, we were lucky to find this school for her" (personal communication, November 6, 2012).

Andrea is about 13 and the *mother* of the Center. She has her eye on all the other students. She is always around to care for those that need a hug, or to be the referee in an argument. She is also the student that David and Praise consult the most when there has been an altercation that one of the staff members might not have seen. She is a caring, loving and very popular student. Andrea and Patricia are inseparable at the Center. As stated in Patricia's profile, Andrea enjoys jumping rope and playing hopscotch. She was competitive during the Center's sports day soccer match.

Andrea has a severe hearing and speech impairment. She is one of the few students I met who was born with hearing loss (many students lose partial or full hearing abilities after illness). Andrea has a brother that lives in Sierra Leone with her father. Her brother is also hard of hearing and her grandfather indicated that the father has a disability as well. Andrea's mother lives in the interior. She divorced Andrea's father after Andrea's birth. Andrea's grandfather stated that she divorced him because

My daughter did the first married; there became two like that [referring to Andrea and her brother's hearing impairments]. Actually there was a problem, so she just decided to leave the man... we are African, we believe in whole lot of things, for that, you know, she is a lady, 'why did I born a first child and the second', so she get decided to just leave the home like that, maybe the problem is from the man or

something is wrong somewhere. She just decide to leave. (personal communication, November 9, 2012)

It was unclear why the brother went to Sierra Leone and not Andrea. When asked why Andrea's brother was in Sierra Leone and not Andrea, he responded,

That is where the father reside now and also the father is sick. He is blind and he too, he can't hear, and really there is no way. We look at her to be a smart somebody. It's only God who find these people who really do well for us. (personal communication, November 6, 2012)

It appeared to the family that Andrea has more ability, so they have chosen to educate her above her brother. It was unclear why the family chose Andrea over her brother.

**Emotional well-being.** According to the grandfather, Andrea is very happy at the Center and in Monrovia compared to the interior village. He stated,

She is happy here. She eats, she play...When she goes home she brings the book and she say, 'papa, this is what I did for the day'. She is improving. So compare at that for when she was in the bush... she is happier here, even when you tell her, let's go to [the interior], she says 'no.' (personal communication, November 6, 2012)

Andrea and her family live directly in front of the mosque her grandfather attends. Andrea does not attend the mosque because, "...most of the time can be her school days, but in the morning, when we got up for pray, we can teach her, she might not hear, but the action, she will know like us with the action. But, like Friday, we can start from

1230... she in school...” (personal communication, November 6, 2012). Her grandfather said that they show her how to pray (personal communication, 17 November 2012), but Andrea does not attend the mosque.

Religion plays an important role in her grandfather’s life. Her grandfather believes that Andrea’s disability is the work of God, he stated, “The problem really is only God, really, at this moment, it’s only God. I can’t open the ear and check or the brain” (personal communication, November 6, 2012). Liberia is very religious country and Andrea’s grandfather’s belief appears to be in line with many of the participants.

Her grandfather has some safety concerns for Andrea because she cannot hear, but it is unclear if those fears reside within Andrea. He stated, “We don’t like her to go around too much because it is danger in Liberia and she can’t hear” (personal communication, November 6, 2012). The same sentiment was echoed by others who were concerned about the safety of people with hearing loss. A school for children with hearing loss has had difficulty with the local police department because some police officers believe people with hearing loss to be crazy (personal communication, November 21, 2012). In addition, the local police department does not have an interpreter, so people with hearing impairments who could sign are not able to communicate.

Andrea appeared to be comfortable and happy at the Center. From observations of Andrea’s interactions with the other students, the conversations with her grandfather and discussion with David and Praise, the Center influences Andrea’s emotional well-being. She laughs and is genuinely happy. She focuses on her studies. She did well on her school exams (see appendix).

**Inter-personal relations.** The grandfather and family seem to have invested a lot into Andrea because the grandfather moved to the Red Light area because of the Center. The grandfather also would like to find a place for Andrea in the United States, “Actually I am asking God if even she can be taken from here to America, there will be no problem the family is willing...” (personal communication, November 6, 2012). Although it appeared to be out of love for the child and a want for a better life, it is unclear if there were other selfish intentions. For Andrea’s grandfather, it seemed more of a plea for support, “You can carry her, I am willing. There are no other means, only you people [I believe he is talking about White people] try to bring life to her fine because we have been asking, but there is no support. I tried” (personal communication, November 6, 2012).

Andrea is very social at the Center. She is friends with all the students. During my time at the Center, she rarely got in arguments with the other students and was often the referee. Her grandfather said,

...she got a lot of friends. Sometimes they will go to the waterside and wash their clothes. They encourage her, they put food together...It was no different because she can’t talk. They will do everything in common. Even now in Monrovia, we will do the same thing in the house. She will eat along even with her small sister. Sometimes we use the same cup to drink. She sleeps in the same room. (personal communication, November 6, 2012)

The grandfather pointed out that they use the same cup and sleep in the same room because it is a common superstition that one can *catch* any disability through contact.

Andrea is well liked at the Center. The Center has provided her with the opportunity to make friends and meet people with hearing, and speech impairments; however, those at the Center do not directly work on inter-personal skills with the children.

**Material well-being.** Andrea's grandfather is optimistic for Andrea's future. He seems to understand the importance of education and sees her further potential. During our conversation, he stated,

If she educated, I think she will be able, if she advance from this school, she can able, she can do, what you people are doing. She can do the same like that...We were getting discouraged about her future because there is no means for her to be educated...so that why we move to Monrovia, she will be part of the society...From what now, I am looking at [Andrea's] future to be educated an even educated woman in our family because her appearing, the way she do things, we are understanding now. She is useful, the only problem is that she can't hear.  
(personal communication, November 6, 2012)

Many Liberian with whom I spoke discussed the *usefulness* of a person. It seems to many Liberians that a person with a disability is not useful because they are not able to provide for their families in the same way a non-disabled peer provides for his or her family.

The Center has provided Andrea with the chance for an education, which could have potential positive repercussions in the future if the climate of stigma and discrimination towards people with disability decreases. There are other places in Monrovia that cater to people with hearing and speech impairments; however, all of the ones of which I am aware, charge tuition.



**Personal development.** Andrea's grandfather believes that Andrea has gained a lot from attending the Center compared to the interior. He stated,

OK, for the interior, the only thing we understand was that when she go, you know, the man down there, he is not trained to what people are doing now. He was not trained as deaf and blind teacher, so he was hard and they advise that if we can bring her here because Monrovia is an open area, maybe you can find some of this schools and we were lucky for this man [referring to David] to bring him here now to compare for that of the interior is 100 percent... it was difficult for the people in the interior. For one they are not trained to teach deaf and blind. They are only trained to teach people that can talk and that can understand well.  
(personal communication, November 6, 2012)

Although the staff at the Center is not trained to educate people with disabilities, the Center was able to hire an ASL teacher for this school year. The addition of the ASL teacher appears to have helped many of the children increase communication, as well as give an example of a person with a disability (the teacher) being a part of mainstream society and not a beggar.

The Center provides a chance for Andrea to stay with her family, which is very important to her grandfather. He stated,

I prefer for her to stay with this school. The reason is that if what they do here is the same thing that they can teach the children on the other school...At this moment now, we prefer for her to be here now. She can be part of the family. For this school, they have not been calling the family for money or bring this only

small money they can call for some activities, like closing... God can do anything, it is only prayer. (personal communication, November 6, 2012)

The tuition-free schooling Andrea is receiving creates an opportunity for Andrea to be part of the family versus the many boarding schools that become dumping groups for students.

When asked why the family did not send Andrea to the local public school, he stated, "...actually, no, because it would be very hard because there is not the support equal to what these people are doing. The government school there would be no way" (personal communication, November 6, 2012). The personalized treatment that each student receives at the Center is not comparable to the overcrowded classes of the government schools.

The grandfather bases his expectation of Andrea on the cultural roles of a woman in Liberia. He stated,

She is useful in the house where we live. She can wash the clothes, she cook, by explaining to her, she can cook... she cook dry rice, put pepper over it. At times, she loves to take care with her smaller ones, now what she can do, you tell her to bring water, she can do. Domestic work, she can do it. At the end of the day, she loves sleeping. (personal communication, November 6, 2012)

The Center did not teach Andrea how to cook or clean, but the Center has helped to make communication easier. Her grandfather stated, "...we try hard for her to be, to teach her with some of our signs. I can talk with her, she can understand me... We are learning her system. We are learning from her now" (personal communication, November 6, 2012).

Communication is difficult, but the Center has provided an avenue for the children to learn to communicate with others that know ASL. Unfortunately, the Center has not been able to conduct a parent ASL program. Many students, like Andrea and Patricia, have gone home to teach their family members and friends a little ASL, which is a positive impact from the Center.

**Physical well-being.** Her grandfather has concerns for her safety, like some of the other caregivers, because of ubiquitous motorbike taxis and cars. He stated, “For her who can hear, you see the vehicles move all around and you can see the motorbike and somebody can just pick her up and you will not go and ask, ‘where are you from?’” (personal communication, November 6, 2012). Her grandfather did teach her to look both directions, but that does not guarantee that a car or motorbike will not be there when you cross the street. Normally, Andrea’s sister will be traveling with her (personal communication, November 6, 2012).

**Self-determination.** Andrea has limited ability to move around the community. Her grandfather stated, “...from school she go to the house and even from there she can go to the grandma in the market to keep time with her to observe things and observe action. You can send her to go and buy. If you describe it, even to go and buy, to go for water, even to bath, you say, like something, sign, you know” (personal communication, November 6, 2012). Andrea’s difficulty with communication limits her abilities to contribute to the family in the same way a non-disabled peer might be able to contribute.

**Social inclusion.** Andrea’s grandfather did not mention any difficulties with social inclusion at the local level. Andrea does not appear to have any difficulty in her

community and during the home visit, she was playing with a small child and was surrounded by other children from the community. The other children in the community communicated with her. Her grandfather stated, “She is fine with the people in the community. People love her, people even give her money. Sometimes people can give her 150, when she gets anything she can bring it to us” (personal communication, November 6, 2012). Andrea is not fluent in ASL, but it appears that she is able to communicate on some level with her family and friends in the community.

**Rights.** Andrea’s grandfather does not see many options for Andrea, except the Center and to go to the United States, if someone could take her, he stated,

It is only this brother [David]...and the school that is here, presently that is trying, you know, tell that wherever they have time...we can go and ask the people also for help, so that they can be a good part of the society too...we have not yet meet the government, you see in Liberia, all these things are hard, when you reach there they say that the man is busy...So at least we can improve some of this for our sick children, children can’t hear and our help is actually 100 percent from these people now. So, the government, if there is anything for the government to do, it is supposed to help these people [the Center], so they can improve us too. If they [the government] can improve them [the Center], then they can improve us too.

During the PTA meeting, Andrea’s grandfather said he would like to go and speak to someone in the government about the rights of people with disabilities, but transportation and funding of transportation is an issue (personal communication, November 18, 2012).

David said that the Center would like to support that, but they do not have the funding, either (personal communication, November 18, 2012).

### **Alexis**

I interviewed Alexis's mother once. I visited Alexis's home and surrounding community twice. Though Alexis's mother was not available either time I attempted to visit, Alexis was and I was able to observe Alexis in her community setting. Alexis's mother participated in the PTA meeting. Alexis lives in a large cement structure with her mother, brother and numerous housemates. Her father sells things in the interior, but comes to visit on occasion. Her mother purchases items in the interior and brings them to Monrovia to re-sell in the local markets. Alexis has lived in Monrovia her whole life. Alexis's brother often picks her up at the Center in the afternoons. Alexis was beginning her second year at the Center when I began my research.

Alexis is a feisty, young first grade student at the Center. She is about 6 years old and enjoys dancing, playing hopscotch and practicing her ASL alphabet. Alexis is hearing impaired. Her mother is unsure what caused her daughter's hearing loss. When she was very young, Alexis got sick, began yelling, "Mama, mama, my ears," and then, according to her mother, stopped talking. Alexis received a hearing aid from the Starkey Hearing Foundation.

**Emotional well-being.** Alexis appears to be a happy, healthy 6-year-old. Her mother stated that Alexis does understand her difference from most other Liberian children (personal communication, October 27, 2012). Her mother said that when Alexis sees other people talking in a group, Alexis would ask her mother if there is something

under her tongue. Her mother will say no and her mother believes that Alexis becomes very sad because she believes that Alexis wants to talk. When Alexis received her hearing aid from the Starkey Foundation, she was very excited at first, and was eager to practice her pronunciation with me; however, after a few hours she continued to wear her hearing aids, but learned how to turn them off. In addition, her hearing aid stayed at the school for the rest of my time in Liberia. I never observed this sad side to Alexis while I was volunteering at the Center. Alexis did get angry and upset, but it was mostly due to someone taking something from her or her belief that someone took something from her. My lack of observation of Alexis's *sad side*, has led me to believe that Alexis feels accepted and enjoys her time at the Center.

Her mother has emotional difficulty with Alexis's disability. She said, "So, myself, it got me embarrassed to that extent that every day I used to be crying, I would cry whole day" (personal communication, October 27, 2012). Since Alexis's enrollment in the Center, her mother has learned to accept her daughter's disability. She stated,

But from the time [Alexis] start coming here...In the morning, I just dress [Alexis] and I bring [Alexis] here. [Alexis] growing fine. She talks some things. She do some things that are not even expect since she been coming here. It made me get that feeling fine to me. (personal communication, October 27, 2012)

This slow acceptance of her daughter's hearing and speech impairment appears to stem from the support of the Center. Alexis's mother stated, "They give me encouragement that [Alexis] will do things for tomorrow. They give me that encouragement" (personal

communication, October 27, 2012). It is unclear how this encouragement will affect Alexis later in life, but one can conclude that the acceptance will have a positive impact.

Alexis gets along well with the other students. She would often share food and play games with Andrea and Patricia. She shows up on a regular basis and does not appear to be upset or crying when she arrives. She usually arrived with a positive demeanor. Based on observation and discussions about Alexis's community life, the Center seems to be a positive emotional environment for Alexis.

Alexis and her mother regularly attend church. Her mother also regularly takes Alexis to prayer clinic. Alexis's mother said that Alexis is welcome and accepted in the church. Religion plays a role in helping Alexis's mother cope with the stress of Alexis's disability. David told me that Alexis's mother often takes her to prayer clinics to try and improve Alexis's hearing impairment. In addition, religion appears to provide a sense of hope for her mother (personal communication, October 27, 2012).

**Inter-personal relations.** Alexis is well liked at the Center and interacted with all the students. She did get upset multiple times at students when she thought they had taken something from her or when she thought something was hers. These actions seem appropriate for a 6-year-old.

In her community, according to her mother, Alexis has friends and she plays with them often. Denise and Alexis live close to each other. When I conducted the visit to Denise's home, Alexis and many other children came to Denise's house to watch. Alexis seemed to get along with the other children. All the children were crowded near a cement wall. This observation in combination with what her mother stated about her friendships

is evidence that some of the children in the community do not exclude Alexis. However, there have been instances when people in the community have accused Alexis of crimes that she did not commit. Her mother recounted this story,

I notice that when I leave her home, something she will not do, when I come home, they say she will do it. They will tell me to pay money. The children when are playing the other day. The other little boy when they play, they play cut. The thing that blessed me, the one woman that passing, she saw the area was not her. They tell me to carry the child to hospital. When we are going, the woman come up to tell me that it was not [Alexis]. (personal communication, October 27, 2012)

Alexis's mother is recounting a time when she returned home from work to find that Alexis had been accused of cutting another child in the community. Alexis appears to have regular cognitive ability, but due to her hearing loss and lack of access to ASL training, she is unable to fully communicate with her mother. Alexis was not able to tell her mother exactly what happened. En route to taking the boy to the hospital, a woman stopped Alexis's mother and said she had seen the whole thing and that it was not Alexis.

Alexis will also fight back when someone appears to be picking on her or upsetting her. Her mother stated, "Sometimes, sometimes people can say she is fussing. Sometimes children can run to me and say...[Alexis] can beat...Sometimes when she is home I beat her butt, then she will know what is she do" (personal communication, October 27, 2012). Her mother believes that these instances are due to Alexis's disability and difficulty with communication. When asked why Alexis gets into fights she said, "Because of her problem, the people consider her that, when she do anything, they must



not do something to her” (personal communication, October 27, 2012). Alexis’s mother is saying that there is a miscommunication between other children and Alexis, and this causes fights between Alexis and the other children. Spanking a child is common practice in Liberia and a majority of the parents with whom I spoke said they spanked their children. In her community, Alexis appears to be accepted, but her mother believes that other children sometimes pick on her; however, Alexis does have a temper and will stand up for herself. Unfortunately, communication issues make it difficult to understand completely Alexis’s role in her community and the depth of her relationships.

Alexis has difficulty communicating with most people outside the Center, including her mother. Her mother said,

...sometimes she wants something and I can’t understand it. Unless she take a sample of it. She give me it. She wanting the candy, she will do it like this (*mimics eating something*). She say I must give her money, she can buy candy. She wanting the orange. She doing the something. For that two things, it just looking the same, so I can’t really understand it. (personal communication, October 27, 2012)

This theme is quite common throughout the lives of all the students and Alexis’s communication difficulties do not appear to be any more or less than other students. In addition, the Center’s influence on Alexis’s inter-personal relationships outside the Center seems low.

I did not have a chance to meet Alexis’s father, but her mother said that Alexis and her father have a positive relationship. “As soon as [she] see her father, she will come

and get her father's slipper and take her father's shoes off. Play with her father, wrestle..." (personal communication, October 27, 2012). There was no other evidence to support Alexis's relationship with her father. As far as I know, she did not talk about her father when I was around.

The impact of the Center on Alexis's inter-personal relationships is not completely clear. She had friends before attending the Center. The Center is helping with communication by teaching Alexis ASL, but without the mother's knowledge of the language, communication still remains a problem.

**Material well-being.** Alexis's mother is very worried about her future. She stated, "I can be thinking if she can be writing, she will know the words, but what thing will [Alexis] do for tomorrow that will benefit her family, is my worry, and I don't really know" (personal communication, October 27, 2012). She was vague on her idea for Alexis's future and had difficulty verbalizing what would happen to Alexis in the future. She is aware that many people that cannot talk or hear end up selling things in the market. She is confident that Alexis could go to University and that the Center will help Alexis to get a job and develop the skills needed for a job (personal communication, October 27, 2012), but she was unclear on a specific job.

**Personal development.** Alexis started attending the Center in the fall of 2011 and her mother believes that the Center has had a positive impact on Alexis's educational development, "They can teach [Alexis]. The [Center] can teach her. I notice that they can teach her" (personal communication, October 27, 2012). This is evidence of the impact the Center has on Alexis's mother's perception of the education at the Center. She also

stated, “To sit and write, to remember words. She was not doing it, but since I start bringing her here, she can do everything” (personal communication, October 27, 2012). She appears to be surprised that the Center is able to teach her daughter.

Her mother did send Alexis to a private pre-school before Alexis’s disability; however, she never tried to send Alexis to public school after she became hearing and speech impaired. She stated, “Her only problem [her lack of verbal skills] will give the teacher hard time” (personal communication, October 27, 2012). This is the common thinking among many of the parents and other Liberians with whom I spoke.

Alexis is motivated to learn and is excited when she learns something new in class. While I was volunteering at the school, Alexis would often practice some of her ASL vocabulary with me, and if my video camera was on, she would stand in front of it and practice the ASL alphabet. She did well on her exam (see appendix) and appeared interested in attending the Center.

**Physical well-being.** Alexis’s mother is concerned for her daughter’s safety when she goes to the market. She said,

When I go to the market, when she come from here, she will go home. People that will beat her, people that will do something, when I come from the market, I go to the house. She would like to explain...I will start feeling bad. There’s something they did to her, she wanted to tell, but she cannot tell me. In that way, I will cry sometimes. (personal communication, October 27, 2012)

Other instances of Alexis's interaction with the community will be addressed in subsequent sections. The physical well-being of Alexis in the community is not something the Center has addressed.

Alexis's mother often takes Alexis to prayer clinics, and she had Alexis's tongue cut because she believed Alexis had a *tied tongue*. Some of these clinics offer medical advice, for example, she said, "When I go, they can give me oil for her to be using in her ear. Anywhere I go they tell me, 'she will talk, she will talk'" (personal communication, October 27, 2012). Another clinic told her that Alexis's father's ancestors put a curse on Alexis because they did not want Alexis to tell her father's family secrets (personal communication, October 27, 2012). Besides that oil for Alexis's ear, her mother stated that she does not give Alexis any other kinds of medication. Alexis's mother does not take her to the hospital for her hearing and speech impairment, only to church clinics (personal conversation, October 27, 2012). The Center does not take a stance on these prayer clinics.

**Self-determination.** Alexis plays with other children in and around the community. Her mother often worries, as shown in previous sections of Alexis's profile. Her mother said, "Sometimes our children, they can run around. Sometimes our neighbors, the video club are there. They go and see show" (personal communication, October 27, 2012). She purchases her own candy in the community. Alexis was also present during the interview of Denise's grandfather, as stated earlier.

Alexis has a very strong will and personality. If she wants something or feels that she has been wronged, she will let one of the adults at the Center know; but it is David

who communicates best with the children. I observed on more than one occasion his ability to solve problems that arose between many of the students, not just Alexis.

**Social inclusion.** As stated earlier, Alexis has some difficulty with communication in the community. The mother believes that some members of the community place blame on Alexis when she has done nothing. Other members of the community will give Alexis money because of her disability. “As for her, from here to the market we will reach, she will get 15 or 25 [Liberian dollars]” (personal communication, October 27, 2012). This is a common practice, as many people with disabilities beg in most marketplaces and in front of supermarkets in Monrovia. Her mother stated that people are respectful of people with disabilities in Liberia because they are willing to give them money (personal communication, October 27, 2012).

Alexis’s mother does not believe that Alexis or any child with a disability should be included in the classroom with his or her non-disabled peers because, “they will not understand them and the teacher too will have problems with them” (personal communication, October 27, 2012).

Alexis’s mother stated that she was willing to send her daughter to a boarding facility; however, she has not sent Alexis away because of the encouragement from the Center. “As for me, I don’t have any government to say, I get her an idea to carry her anywhere. I accept for her to go away from me, but they encouraged me to bring [Alexis]” (personal communication, October 27, 2012). It appears that Alexis’s mother wants to send her to a school so that she can learn because she stated, “I can send [Alexis] away. I want for her to learn” (personal communication, October 27, 2012).

**Rights.** When asked about the government, Alexis's mother did not mention that the people with disabilities needed more rights. She simply wants the government to financially support organizations like the Center. She stated, "We ask the government to help people that are helping us because if they get everything like the support, they will try to help us, but if the government can't help them they will not be able to help her [Alexis]" (personal communication, October 27, 2012). She suggested that the government build a school for people with disabilities and give money to the school for notebooks (personal communication, October 27, 2012). Outside of the PTA meeting, there appeared to be little discussion about the rights of people with disabilities with Alexis's mother.

### **Kevin**

Kevin is one of the Center's older students at 15. He lives with his mother near the Center. He is the only student that is able to communicate verbally. I was able to interview his mother twice, once at the Center and the second time during a home visit. David attended both interviews with me as Kevin's mother had a very thick accent and at times, I was not able to understand everything she said. His mother also attended the PTA meeting. I was also able to interview Kevin once. Kevin was very shy during the interview and it was hard to obtain information about his life outside the Center. This profile will rely on information obtained from both his mother's and his interviews, as well as observation and various documents.

He is a smart young man and has attended the Center for two years. He is in the upper class. His mother sent him to school as a child, but she was afraid he would have a "fit" at school (personal communication, November 27, 2012), so she kept him home a

lot. Kevin missed a lot of school until a few years ago when his mother found the Center. Kevin enjoys singing and playing soccer. He has started the year off strong by obtaining A's and B's on all of his exams for the 1<sup>st</sup> quarter (see appendix). He is working hard to learn sign language, but has difficulty with ASL because he cannot use his left hand and ASL uses both hands.

Kevin has epilepsy and limited use of the left hand and foot. He is able to walk, but with a slight limp that is barely visible. He is the only student at the Center with solely a physical disability.

**Emotional well-being.** Kevin appears to be a happy person and he stated that he is happy attending the Center (personal communication, November 26, 2012). Kevin was usually happy at the Center. He was eager to participate in the classroom and would help his classmates when they did not understand something.

Kevin's mother is a religious woman and mentioned, "give it to God" multiple times during the interviews (personal communication, October 27, 2012), but Kevin did not mention God or attending church. Kevin's mother also stated that she has attended a prayer session by the evangelical preacher, Franklin Graham, for Kevin.

The Center positively influences Kevin's emotional well-being. He stated on numerous occasions during our interview that he likes the school and that he was happy there (personal communication, November 26, 2012).

**Inter-personal relations.** Kevin is well liked at the Center and will play with all the students. He attended on a regular basis and paid attention in class. There were times when Kevin acted as a translator. For example, I tried to explain that  $3 + 5$  and  $5 + 3$

equaled 8, but most of the students did not understand. Kevin tried to explain the problem to the other students in the upper class. Although neither he, nor I, were able to make the students understand, the other students were quiet and paid attention to both of us.

Kevin stated that he does not have any problems in the community and his friends do not pick on him or make fun of him (personal communication, November 26, 2012). His mother was unsure of his relationship with his friends, but David stated that his friends do not pick on him because, “I have seen...I know some of his friends. They have all accepted [Kevin]” (personal communication, October 27, 2012).

Kevin’s father lives in the interior and his mother stated, “He [Kevin’s father] show him [Kevin] good face, he can’t beat him” (personal communication, October 27, 2012). Kevin did not mention his father in our conversation or during any other observations.

**Material well-being.** Kevin’s mother believes that if Kevin finishes school, he will be able to get a job. Kevin is old enough that he does odd jobs around the community, like selling sand (personal communication, October 27, 2012) and Kevin reported that, “People can pass by and people can give me money. I can work for them. I will help to clean their yards” (personal communication, November 26, 2012).

Kevin and his mother hope that he can get a better job once he is finished with school. His mother stated, “He must go to school. He must go learn any job” (personal communication, October 27, 2012). Kevin said, “I want to learn something so my mom will enjoy me” (personal communication, November 26, 2012). David translated this as, “He wants to learn something so tomorrow [in the future] his mother will benefit...”



(personal communication, November 26, 2012). Kevin ended our conversation when he stated, “I want to be doctor. I will learn book. I will go to school for plenty years, to support my mother” (personal communication, November 26, 2012).

The Center is influencing Kevin’s future by teaching him skills, such as ASL and math. Since Kevin appears to have normal cognitive functions, and his disability is physical rather than sensory, he will likely have an easier time finding a job over some of the other students.

**Personal development.** While conducting my research, the upper class was learning single-digit addition and subtraction. Kevin learned addition quickly and moved on to single-digit subtraction, while the rest of the class focused on mastering addition (see appendix). His mother feels that the Center has helped him to learn numbers and letters, and Kevin stated, “I learned plenty things...math, spelling, English” (personal communication, November 27, 2012).

Kevin’s mother did not attend school, so the Center has a positive influence on Kevin’s personal development. He can write letters, identify letters, sign the alphabet and various vocabulary words, and do simple math.

**Physical well-being.** Kevin’s mother only fears for Kevin’s safety because of his seizures; however, this does not limit Kevin to staying in the house. He does go around the community with his friends, helps his mother in the community garden, and works on odd jobs. Kevin does not cook because his mother fears he might have a seizure. His mother stated, “When he hungry, he can go for dry rice. He don’t cook because he of the fit” (personal conversation, October 26, 2012).

Kevin's mother rubs *chalk* on him at night and she stated that the *chalk* has helped to alleviate some of the seizures (personal communication, November 17, 2012). She obtained the chalk on a recent trip to Guinea to visit her sister. She stated, "The woman tell, she said, it very common on there and the same sickness can be done and they can go there and the sickness can finish and I can go there and they give me the medicine" (personal communication, November 17, 2012). In addition, his mother stated that he has a seizure approximately once a month (personal communication, November 17, 2012), unlike Terri who has a seizure once a day when not on her medication.

**Self-determination.** Kevin makes most of his own decisions. His mother said that she must cook for him and help him with his belt because of his left hand. Kevin appears to have the most freedom compared to the other students at the Center. Kevin is also the oldest in the Center and because he does not have a disability that affects his cognitive functioning, hearing or speech, he is not targeted as much as other students. Kevin's mother will give her son money to get food, or Kevin is able to earn his own money around the community; however, Kevin's mother said that she does not send Kevin to the market because he is not good with money (personal communication, October 26, 2012). The Center has not directly influenced Kevin's self-determination.

**Social inclusion.** Kevin appears to be more accepted by his community than the other students. This might be because his seizures happen infrequently and his is a mild physical disability. Kevin has friends and is regularly seen in the community walking around with them. He and his mother did not recount any difficulties or discrimination Kevin faces in the community. Kevin attends the Center because his mother believes he is unable to go to school because of his epilepsy.

**Rights.** Kevin could attend school, but his mother is afraid that he will have a seizure while at school and she does not have money to pay the fees (personal communication, October 26, 2012). Although school is supposed to be free, many public schools require students to pay fees for books, uniforms and other items.

### **Profiles of the Students: Lower Class**

Terri, Denise, Joseph and Mary are in the lower class. The lower class is occasionally taught by the director's wife, Praise, who reviews the alphabet, sings, and on one occasion allowed Terri to tell a story. The students in the lower class have more severe cognitive disabilities. The lack of resources and training have an impact on the ability of Praise and others to properly teach student with more severe cognitive disabilities.

#### **Joseph**

Joseph is one of the veteran students since he started attending the school when it opened in 2009. He is approximately 9 years old. He is usually a happy boy who likes to tell you secrets. He will walk up to you and whisper things in your ear, though he has a very severe speech impairment and can only say a few words. Joseph loves cars. Whenever a car or motorbike passes the Center, he is the first one to the window to let everyone know. Joseph lives with his mother, father and many other family members in a house just outside of the Red Light area in Paynesville. His father is a mechanic and his mother is a nurse and runs a pharmacy located next to their house. Joseph had a younger brother who died. Joseph is lucky to have both parents and an aunt that keep a close eye on him, as it appears to be a rarity in Liberia.

Joseph has the most severe behavior problems in the Center. It is unclear with which disability he lives. His mother and father have spent thousands of dollars and gone to numerous hospitals with no diagnosis. One doctor said Joseph needed an operation on his brain and another told his parents he did not need an operation (personal communication, October 24, 2012). I am not a specialist in Autism, but Joseph has a few characteristics of the disorder. His mother stated that he did not cry until he was almost 6 months old and,

He was very hefty, he was fat, I thought it was the polio, but I took him to Redemption, JFK, it was nothing really there. I said he got sick and he reduce [lost weight] because he got small. Since then for him to walk, it was very hard, but then we try, try, try, but then at the age of 2 years and 10 months before he could walking and then his spit used to come down. At first, it was not coming down, but at that time it started coming down. (personal communication, November 17, 2012)

Joseph has an oral fixation and carries a small rag with him on which to chew. Joseph has low-fine motor skills, but can walk and definitely run with relative ease. He is obsessed with cars, keys and feet. Joseph needs constant supervision and will sometimes run out of the building. If the door is locked, but the key is within sight, he will steal the key and run. He is mostly non-verbal, although he can say a handful of words. He can answer yes or no questions and will become very agitated when he does not get his way. One major problem the Center faces with Joseph is getting him to keep his clothes on. He will often strip naked in the afternoons after lunch. The Center used to bathe Joseph after lunch and there is a suspicion that this could be the cause of his desire to change clothes

after lunch. Joseph does as well as is expected and he is a nice, wonderful young man... when he wants to be.

**Emotional well-being.** Joseph's emotional well-being seems quite normal for a child his age and ability. The Center has added to Joseph's daily happiness. His mother stated,

Sometimes when I get tired, I will say, Joseph today, you will not go to school. He will take his book bag and say, no. I will talk, talk until I will find him transportation and call ...to come and bring him here, but like the other school that I took him the first time. The first school when I used to say, he would cry. I used to prepare food every day and everything. He would be crying and he would say he don't want to go. (personal communication, October 24, 2012)

The mother's emotional well-being has also increased since Joseph began attending the Center. Before Joseph's attending the Center, he would stay at home and his mother could not leave the house. She said, "Since he started attending here I have been free... They helping us, but mainly they helping me, because it was like, I was, sometimes I used to be embarrassed I can't leave him with anyone to go out" (personal communication, October 24, 2012). From the mother's remarks and observations, the Center positively influences Joseph's emotional well-being.

**Inter-personal relations.** Joseph is very close with his aunt, who is about 10 or 11. He will often follow her to her school in the evening. The mother said that he does not have any problems when he is with his aunt and that, "When she goes to the study class, he will go there. Although he don't do what they are doing, but still he will be

there” (personal communication, October 24, 2012). Besides, Joseph’s mother and his aunt, it appears the Center is the only other place Joseph has friends.

At the Center, Joseph will play with other students. The students will sometimes become frustrated with Joseph’s behavior. Joseph can be very aggressive and not appear to comprehend the effects of his actions. There were many times when Joseph would cry and become distraught because he was not included in the upper class activities. The staff at the Center had a difficult time modifying the behavior to increase more positive behavior in Joseph. I never saw staff abuse or neglect Joseph; in fact, the staff appeared very concerned about Joseph, asking me questions about what they could do to help him or why his disability manifested in such a way.

**Material well-being.** Like other parents, Joseph’s mother is unclear about her son’s future. She wants him to learn and sees the Center as a venue for that, but was very vague on an actual job he could do in Liberia. She stated, “My hope is, I want him to learn, I want him to learn, at least to do something for his self” (personal communication, November 17, 2012). When pushed a little in a following question about a specific job and Joseph’s future, she stated, “I can’t say it” (personal communication, November 17, 2012).

Joseph’s father is a mechanic and his mother stated,

[Joseph] loves car business. I think he can see his father’s car business; we can save this for him. All day he is in that (*she pointed to van sitting in front of their home*) day, what he doing, we don’t know. He will take the mat and put it under the car, he will go for the tools and start to work with it, but we don’t have a

mechanic job, yeah, so we only be looking at him. (personal communication, November 17, 2012)

Joseph's mother wants him to learn enough to get a job; she does not see a future in Liberia for someone with Joseph's disability. When asked about Liberia and Joseph's future, she stated,

I don't want him to remain like this, yea, I don't want him to remain like this because if he remain like this, we will continue to work for him and want him, at least, if he can able to work for hisself, I'll be very happy... Actually, I have not seen it [people with disabilities working in Liberia]. At least, if he can able to read and write, I think he can get help, but not well, if he not able to do anything at all.... (personal communication, November 17, 2012)

Joseph's future is uncertain. The Center does not have a vocational training center to help Joseph learn a trade. Joseph's differences and cognitive challenges impede his ability to carry out normal job functions. Even if Joseph were in the United States, which has many programs for people with severe cognitive disabilities, the chances of Joseph earning an income and living on his own are slim.

**Personal development.** Joseph's mother truly believes that there has been a change in Joseph's behavior because of the Center; however, these changes could also be because Joseph is older and his behaviors are changing with age. When asked if she has seen any changes in Joseph's behavior since beginning the Center three years ago, she stated,

Yes, gradually, he is changing. Sometimes we used to do anything, you used to tell him stop, he used to just go ahead and do it but since he been here when you call him he will give the attention to you...Like I am saying, at the time he was home when you tell him don't do this, he will do it. (personal communication, October 24, 2012)

His mother attributes his ability to brush his teeth and bath himself to skills he learned at the Center (personal communication, October 24, 2012).

When asked if the Center gave her hope for the future, she stated,

Yes (*very enthusiastically*). Well, as he started, gradually he was able to do some things, like writing. He used to hold pencil (*the wrong way*). So, gradually, one day he will be able to write and if he able to write and read, then I think, he can do better things. (personal communication, November 17, 2012)

Although Joseph is in the lower class, he often sits in on the upper class. It appears that Joseph likes to sit in with the upper class because they have a more structured school day with more challenging activities. On the few days when the lower class had a more structured lesson plan, Joseph would sit in there. He loves to write and learn ASL. He does have difficulty with the signs because of his lack of fine motor skills, but he tries very hard and will practice while in class. His mother is confident in the teaching methods at the Center; she stated,

Yes. They teaching system, what really they are doing now, I was just observing the sign when they doing it and they can explain to me and I see [Joseph] doing it.



I am impressed. Others can't talk, but at least they can do that. We praise God for that. (personal communication, October 24, 2012)

Joseph's mother thinks the Center has made a difference in Joseph's behavior and his ability to sign, although Joseph's mother does not understand ASL. The teacher in the upper class included Joseph in many of the lessons and he learned a few signs.

Unfortunately, the Center does not have a behavior modification plan in place (although there was one in Ghana) and Joseph's behavior can be uncontrollable. There are small steps that have influenced Joseph's personal development.

**Physical well-being.** Joseph has attended other schools, but his mother stated,

He was in the school, but every time he would come, you would see the knot all in his hair and in his skin. They say he and his friends used to fight, but later I had to take him from there. The second school, I did his registration, I did his tuition everything, but then he went to school for only day and the next day they called me and said they couldn't do it. (personal communication, October 24, 2012)

Joseph has also experienced discrimination in his community. His mother recalled this story,

Some many day, sometimes when they are eating, when Joseph is eating, they will come and eat with him, but then when they are eating their only food and Joseph will go, they will say, 'Oh, you, go, you nasty, you come in the area, nasty.' (personal communication, October 24, 2012)

The Center has a lot of difficulty with Joseph, but I never saw anyone at the Center physically abuse Joseph. When Joseph was acting out, they would carry him to a classroom and shut the door. Joseph would often cry, calm down and then they would let him out. The Center is a safe place for Joseph, whose behavior can be very difficult.

**Self-determination.** Joseph makes his own decisions. When I conducted his home visit, he had just finished washing his shoes and just before I left, he purchased a piece of bread and butter from a vendor walking around the community.

Joseph plays a lot according to his mother. When asked what Joseph does on the weekends, she stated,

Hmm... *laughing*... he play. When he get up and sometimes he get up at 4 in the morning and he want to get us up. So if the iron gate is not locked he want to get out and he disturbing until someone open the door, he get outside. He get out and he will get to the man in the area, he always call the man, papa, so he go to visit the man from there he come...he eat, he will play throughout. You tell him come sleep, he will not sleep. (personal communication, October 24, 2012)

**Social inclusion.** Joseph and his family attend church. His mother often referred to God when discussing the different ways in which she copes with Joseph and his disability. Not all church members accept Joseph. His mother stated, “some people, I say go to them, they will sharpen, ‘oh, the boy is fire, he is not sound, he is not human being’” (personal communication, November 17, 2012). During our first interview, Joseph’s mother said that when her other son passed away, some people in the church believed she had sacrificed her younger son in an attempt to save Joseph (personal

communication, October 24, 2012). These beliefs are consistent with some of the observations of local NGO workers that were discussed in Chapter 3.

Although Joseph's mother has tried to place Joseph in a school with his non-disabled peers, it has not worked out. Joseph came home with bruises from one school and was only allowed to attend the other school for one day. His mother hopes that one day Joseph can attend a regular public school and sees the social value of her son attending a school with his non-disabled peers. When asked about including children with disabilities in the general education classroom, she stated,

Well, what I can say, if they try, like they can mix them, at least they can be looking at their friends, what they're doing and their self will be able to do it, but if you say, you put some of them together, maybe only the teacher will be helping them to teach them and if the teacher is not around they won't do anything, but if others children are around and they are looking at them doing something, I guess some of them will be able to do something too. (personal communication, October 24, 2012)

This last half of the quotation is quite telling on her view of the educational system in Liberia. She understands the difficulty with teacher attendance and knows what happens to the children when the teacher is not there.

Although the Center has never provided a community training on those with autism, it has given Joseph a school, place to belong, and friends. He is included in the school and has a larger community than before attending the school. He was the 2011-

2012 *Center* king. Joseph appeared to be proud to be king when he showed me his crown. His mother had professional photos done for the ceremony.

**Rights.** Joseph's mother felt that Joseph and other people with disabilities deserved more rights, like the right to an inclusive education (personal communication, October 24, 2012). In the last section on social inclusion, she pointed to the need of peer examples.

### **Terri**

Terri is one of the older students at the Center, possibly 15, but her exact age is unknown (personal communication, November 22, 2012). She has attended the Center for a little over a year. Before attending the Center, Terri would help her mother sell fish in the market (personal communication, November 22, 2012). Terri lives with her mother and stepfather (personal communication, November 22, 2012). She has two brothers, both of whom are living with relatives that are more affluent and attending school (personal communication, November 22, 2012). Due to Terri's illness, she resides with her mother and attends the Center (personal communication, November 22, 2012). I only had the opportunity to interview Terri's mother once, but she stopped by the school on other occasions and attended the PTA meeting. At the time of research, Terri and her family were evicted from their home due to the stigma surrounding epilepsy (personal communication, November 22, 2012).

Terri is a quiet, focused individual who prefers small group settings. She likes to sing and recite the alphabet. She is a great storyteller and enjoys standing in front of the

class to tell a story on the fly from her imagination. Terri is one of the students in the lower class.

Terri suffers from epilepsy, and possibly mental retardation. Her mother said that Terri would have an epileptic attack every day without “the tablet.” Her mother does not remember when the *spells* began, but Terri would have them every day until a friend of her mother suggested she go to the pharmacy and get a tablet that would help control the seizures.

**Emotional well-being.** Terri’s demeanor appears to be very cold. She does not appear to be a happy individual. She does not like other students to touch her or even sit next to her. However, she does interact with a few of the students and will break into a smile when talking to Denise or telling a story in class. Terri does not like commotion, fast movements or groups. During most school functions when everyone at the Center was sitting in the front lobby, Terri could be found sitting on a bench (usually with Denise) away from the other students. She would often hit or curse at other students if they touched her. Praise described her as *crabby*. Despite her demeanor, the staff and other students welcomed Terri into the school after her three-week hiatus, which will be discussed further in her profile. Denise was the happiest to see her. Despite her somewhat hostile demeanor, Terri’s mother has noticed a positive change in her behavior since attending the Center, she stated,

...if the man tell her anything to do, she will curse the man, but since she start coming here, in the morning, she will go to the man and start saying, papa,

morning-oh. All that ones she be doing it now. When I not around, the man can bring her [to the center]. (personal communication, November 22, 2011)

Terri and her mother attend church every Sunday. Her mother did not state whether the church accepted Terri.

Although Terri has a more anti-social demeanor, she had friends at the Center. She smiled and laughed when she did not seem over-stimulated by the commotion. It appeared that none of the students intentionally targeted her for harassment and the staff were always polite. This has led me to infer that Terri's emotional well-being was positively influenced by the Center, although it is more unclear in her case than in the other students.

**Inter-personal relations.** I was not able to observe Terri in her community, but her mother stated the community members stay away from her because of, "The sickness...and the way she mood, you touch her, she curse you" (personal communication, November 22, 2012). However, she also stated,

No, the community we live in, the people love her. They can want to play with her, she get vexed [angry] with them, the same thing she doing here. In yard now, she don't want for nobody to play with her. (personal communication, November 22, 2012)

When asked a third time about friends in the community, Terri's mother laughed and stated, "Who would be friendly with her" (personal communication, November 22, 2012). Her mother believes that people in the community think Terri's epilepsy is

contagious. She said, “Isn’t that how they say what they scared for, but me, we can eat together, why that can’t catch me too” (personal communication, November 22, 2012).

Terri’s extended family is scared of Terri because of the epilepsy. Her mother stated, “[Terri] is not loved by her family. Her pa died in the war and her pa’s sister, they scared of her” (personal communication, November 22, 2012). However, Terri’s mother and stepfather do care for her; her mother said, “The man love her, the man give her money, buy clothes, slippers, the man bring it. Before the man bring it, she not satisfied, she curse the man, but when she start coming here, but now she stop” (personal communication, November 22, 2012). Terri’s mother feels that the Center has helped Terri to develop inter-personal skills because she is more appreciative of her stepfather.

Terri’s mother is religious and she said that she prays every day for Terri’s health and, “that this sickness will go away” (personal communication, November 22, 2012). Terri’s mother appears to be conscientious of the severity of her daughter’s illness. Terri’s mother stated, “When there is no tablet, I can feel bad alone and just go in the market...” (personal communication, November 22, 2012).

The Center has given Terri the opportunity to develop positive inter-personal relationships outside of her community. According to her mother, her relationship with her stepfather became more positive after she began attending the Center. Although the Center does not explicitly teach the development of inter-personal relationships, it is possible that the positive relationship examples at the Center helped Terri in her home life.

**Material well-being.** Terri's mother is unsure about the future. She would be willing to send Terri to anyone that could help Terri get a job; she stated, "She is not looking like this, if somebody say that they want to take her, they take her, then they will teach her a job, but, one thing I will tell her to do, she will do" (personal communication, November 22, 2012).

She is also concerned about Terri's future because Terri's mother is the only one that can provide food. She said, "Yea. I'm the one who can give her. Who will give her food?" (personal communication, November 22, 2012).

Terri's future is uncertain. There is little chance she will find a job without intense, focused education and access to medication to control her seizures. The Center has not held any community awareness programs on epilepsy. On many occasions, the lower class just sat in the room with one of the staff members.

**Personal development.** At home, her mother has taught Terri various household duties for a Liberian woman, like "sweep, go for water, wash clothes for me, she can cook, when the thing [seizures] not coming, but when the thing is coming she not able to do nothing" (personal communication, November 22, 2012) during the day. Her mother stated that she never sent Terri to school because of the fees and she did not send Terri to be with her brothers who are attending school and live with a family friend because of the seizures (personal communication, November 22, 2012).

When asked whether she thought Terri was learning from the Center, she stated, "Yea –oh – when she go home, she can say her ABCs, she say her 123, and nobody is teaching her to the house. Her self can sit down and do all" (personal communication,



November 22, 2012). In class, Terri was able to say the alphabet, but she had difficulty identifying letters and numbers.

The Center has taught Terri some very basic skills, like her alphabet and some numbers. The Center does not have a sustained educational program for the lower class, so growth from that is unclear.

**Physical Well-Being.** Terri's epilepsy has never been formally diagnosed. Her mother began giving her Phenobarbital based on the recommendation of a friend in the market. She recalled this story,

...some people say carry her to the pray people, carry her to the medicine man, when I got to the pray people, they say, they [say] spend 1,000, but I spend it for nothing because she can't get well. I carry her to medicine man, that for nothing she can't get well, so when we move here, I start selling and when I was selling she fall down on the ground fainting and my friend there say, 'well, what happen' and I explained it to the girl. They say no, this thing here is not the prayer business, no hospital business, this fainting business here, they get tablet for it.

Terri's mother's friend told her,

The pray people, say, 'oh, that evil spirit' and I just pay the money, but it the evil spirit can't go, so my friend said that 'don't carry her to no prayer people, the people lie, they want money', but the doctor said that epilepsy, say you get tablet, but I don't know what is it in the tablet. (personal communication, November 22, 2012)

Unfortunately, the pharmacy ran out of the medication and Terri's mother is not sure what she will do. She stated,

That small thing, every day buy the tablet, every day, I am buying it, because when I going to the store, they say that they ain't get the Phenobarbital, they get Phenobarbital that can work the same as the Phenobarbital, so at that time, I buying for her, so that the other tablet, she cannot fall down and the man said that she must take it for one year and that after one year, she can't fall down again, so that the one I buy. (personal communication, November 22, 2012)

During my research, Terri's mother was evicted from their home. Terri's mother believes it is because of Terri's epilepsy; she stated,

...they can tell him, but they can't tell me, only when I go in the market, when I take my basket, to the place where Mary always see me, when the rainfall and I say the rain can enter into the house, so in the morning now, when I go into the market, when I leave the house, you know the people that...all of them will go together and say, 'why you keeping them here, you know that woman daughter can fall down and you get them and you say you want rent from you... Anytime, when she fall down in the gutter and she will die in the gutter and government will hold everybody here responsible', so the landlord say, 'let me just get them.' (personal communication, November 22, 2012)

At this point, in mid-October 2012, Terri stopped attending the Center for approximately 1 month. Her mother stated that she was not able to bring Terri to the school because she needed to be in the market to earn money for their new home that had yet to be built and

she feared that Terri would get lost if she were to walk by herself (personal conversation, November 22, 2012). Terri's case appears to be the most extreme out of the families at the Center. Terri faces discrimination and stigmatization in her community that has led to the eviction of her family from their home.

**Self-determination.** Terri is allowed to walk around and purchase needed items, but she must have exact change. Her mother stated, "...when you give her money to go buy something, you give her the 10 dollars, 5 dollars, but when you give her the 20 dollar or the 50 dollar, she will leave the change and then come" (personal communication, November 22, 2012). In addition, Terri is not allowed to go to video clubs or simply wander the community because her mother fears that she will have a seizure (personal communication, November 22, 2012).

**Social inclusion.** Terri has few friends in the community and is not included in many activities, like the video club, like other students. Terri's demeanor and her disability make her one of the most marginalized individuals at the school, as has been shown in other areas of this profile. She is avoided in her community, her mother fears that she and her husband are the only ones that will ever be able to provide for Terri. The Center has helped to teach Terri basic skills like her alphabet and slowly she is learning her numbers, but these skills have not transferred to her acceptance by the community.

**Rights.** Terri's mother did not discuss Terri's right to an education; she stated that she would send Terri to school, if the school were completely free because she cannot pay the fees. She stated that children without disabilities would come to the Center because the Center is completely free (personal communication, November 22, 2012).

Terri's mother felt that the government needed to do more to help people with disabilities get a job (personal communication, November 22, 2012).

The Center has only influenced Terri's right to attend school by opening the Center. Terri's right to education is not enforced because the Liberian government does not have any trained teachers and the Center does not prioritize the educational needs of the lower class.

### **Denise**

Denise lives with her grandparents in Paynesville. I was able to interview both grandparents and conduct one home visit. I interviewed the grandfather on the home visit and the grandmother came to the Center.

Denise is a happy, but shy 13-year-old girl with a developmental delay. She has attended the Center for 2 years. Denise has difficulty retaining information and has a severe speech impairment. It is difficult to communicate with Denise because she does not talk and she is not learning ASL. She loves to play kickball. Mary, Terri and Denise spend a lot of time together at the Center.

**Emotional well-being.** Denise appeared to be very happy most of the time. There was one day that she arrived at the Center crying. Her grandfather told the staff that she wanted to wear an old pair of shoes and he would not let her wear the old shoes because she was going to school (personal communication, December 6, 2012). Her grandfather also stated that sometimes Denise could be very stubborn.

There are certain time when she got her good spirit on her, she can work, sometime time for school, [Denise] spirits, you can carry to school. Certain times,

stubbornness just get in her. She don't want to go to school. You will talk with [Denise] and it like talking to bush...she will not even move. Sometime she cry while you carry her to school from start to end. (personal communication, October 21, 2012)

Denise's grandparents discussed God a lot during the interviews, but Denise's spirituality is unclear. Her grandfather often goes to church and prays for a cure for Denise. He stated, "I go to church, pray about it, and ask God to cure her. I ask God to take away that disability from [Denise]. It is my prayer every time when I go to church" (personal communication, October 21, 2012). Her grandmother's discussions about God fall under different sections of this profile.

It is unclear how the Center has influenced Denise's emotional well-being. She was very excited every time I arrived and greeted me with a hug. Denise's grandmother stated that Denise is more likely to help around the house and appears to more active, which could point to an influence from the Center. Denise does have friends and appears to enjoy her time at the Center.

**Inter-personal relations.** Denise's mother abandoned her and Denise's father does not play a prominent role in her life. Her grandmother stated,

The mother abandoned [Denise], for 10 years now, they cannot come to the house. Everything left with my husband, [Denise's] father, and me. The family do not even come there... they don't have time. Last week... I ask her [the mother], why did you abandon your daughter, she said 'ma, sorry-oh'. I said, 'no, that is not sorry. What you do, God will pay you for it. You still born the other children

are normal because of [Denise], the way she looking, she didn't do it by herself, God knows why...' (personal communication, December 13, 2012)

Denise does have friends in the community. While I interviewed the grandfather, several children came and sat on the porch. Denise shared some candy with a small child there and then began eating food and sharing it with some of the other children. The children did not pull back from Denise or make odd faces. Denise appeared to be comfortable enough around the children to share candy and food. Her grandfather corroborated this when he stated, "Yes. She get along with other children in the community. They go around, she have friends, she play with friends, she goes along with others in the community" (personal communication, October 21, 2012). The grandmother helped her acceptance in the community. Denise's grandmother stated that children used to pick on Denise, but her grandmother visited all the parents and told them,

If you continue to harm [Denise], I will carry you to court. You girls that are born, you don't know how it will look when I put curse. One of you can born any kind of ugly child too. You leave me. You don't let me get vexed. (personal communication, December 13, 2012)

Denise's grandmother threatened the community and it appears the community has grown to accept Denise more. It is unclear if that acceptance is out of fear or true acceptance.

Denise's grandparents did not mention the influence the Center has on her inter-personal relationships. David stated that he spoke with Denise's grandparents,

encouraging them to love her, but it is unclear if those discussions have influence in Denise's life.

**Material well-being.** Denise's future is unclear to her grandparents. Her grandmother stated, "I pray to God every night let God touch their heart at least to carry them, maybe God will tell them to give them helping hand to do brain surgery, like that" (personal communication, December 13, 2012) and her grandfather said,

I know that God is in control and that God is taking care of her and God is carrying her true. I believe that one day, one day, she will not remain like that forever. She will become a sound person in the future. Presently now, I don't have any fear about what will happen to her or her condition, but I think, that God is in control, everything. (personal communication, October 21, 2012)

Like many of the other students, Denise's future is unclear. The Center has helped to teach her some minimal skills, but she still cannot identify letters and the educational programming for the lower class is sporadic.

**Personal development.** Denise's grandfather believes that, "She have some mental problems, yes, she can't talk well, yes, so she got some mental problems" (personal communication, October 21, 2012), but her grandfather attributes Denise's improvement to her attendance at the Center,

...there are some things that [Denise] used to do that even, you know, she could do by now, even as I am saying now, [Denise] used to bring water for people. I believe that through [the Center] she manages to do all of those things now. You tell her go for water. She go for water for you. I think that a lot of things that [the

Center] is doing that improving the life of [Denise]. (personal communication, October 21, 2012)

Her grandmother believes that the Center has helped Denise. When asked if she likes the Center, her grandmother responded,

Yes, I love it. Yes, differences. The last time [Denise] went home, she started saying ABC, 123. I said, 'oh'. She said, 'Mommy we got teacher in the class. I can go and write'. She was not speaking before. Presently now, her words are getting clearer. I praying to God that she will continue. The first time she just the bobo. This time she is active. (personal communication, December 13, 2012)

The Center has influenced Denise's personal development according to her grandfather. She is more likely to help around the house, she can recite the alphabet and some numbers, and she is speaking a little more.

**Physical well-being.** Denise's grandmother has ensured Denise's safety in the community by walking around to all the houses and telling everyone that if something happens to Denise that person will have to answer to her. She stated,

I tell people that their eyes should be on her because she is not well and she's friendly... I go to the community and I say anyone that harming this child here, try to do that funny thing, because she reaching that age now, you will not live to tell the story. Yes, I say, I will put you somewhere, you will not get women in your



life. I will punish you and when I reach God, I will talk it there. So the boys don't bother her. She intact.<sup>8</sup> (personal communication, December 13, 2012)

Denise's grandmother also spoke to Denise about people in the community harming Denise. During our conversation, she recalled taking Denise into a room, removing all of Denise's clothes and told Denise that if someone tries to remove her underwear, Denise is supposed to scream (personal communication, December 13, 2012). There was one instance when this happened. The grandmother stated that a boy took Denise into an abandoned building and tried to remove her clothes. Denise screamed and the family came running and, "beat the boy" (personal communication, December 13, 2012). Vigilante justice is quite common in Liberia, where many people appear to not trust and even fear the police. Her grandmother took her to the local clinic to make sure Denise was, "intact" (personal communication, December 13, 2012).

**Self-determination.** Her grandmother's threat to the community regarding Denise's safety has afforded Denise the opportunity to go to most places around her house. Her grandmother said,

When [Denise] get up in the morning she walk to everywhere. When she get home from school and she is done eating, she go outside., She go sit in the movie,

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<sup>8</sup> *Intact* refers to not having had any sexual activity. I heard this phrase once before. A small child was playing in front of the Center during the sports day celebrating the third anniversary. A woman began yelling and a young man was accused of removing the little girl's underwear. There was a large crowd and the young man ran off, followed by some other men chasing him, presumable to beat him, according to Praise. Praise brought the little girl to her mother, an employee of the Center. The mother began beating the child for *letting* the man remove her underwear. Praise said she explained to the mother that it was not the child's fault; it was the young man's. I asked Praise if the child should go to the clinic and Praise responded, "No, she is fine, he didn't do anything, she is intact" (personal communication, December 11, 2012).

she love the video club and they know her, the woman, I know her, I told her that their eyes should be on her, even boys that own the video club, they like [Denise], they say [Denise] is their wife. (personal communication, December 13, 2012)

The Center provides Denise with a place to be and call her school, but with such little focus on the lower classes education, there is little evidence to support the Center's influence on Denise's ability to choose things for herself.

**Social inclusion.** Denise did not attend a school with her non-disabled peers because,

...she cannot speak well, that's why we never sent her to regular school. We decided to send her to [the Center] because she be able to improve at which time we will be able to send her to regular school so she will be able to learn something. (personal communication, October 21, 2012)

Denise's grandparents attempted to send Denise to a public school, but the teacher,

"catch hard times with Denise, so we decided to take her from there" (personal communication, October 21, 2012). The grandfather would not elaborate on the *hard times* with the teacher; he just repeated that she left the school. Her grandfather stated that there were not any problems with the other children or the teacher, but that they decided to remove Denise from the school because Denise wasn't retaining anything she learned in class and referred to the *hard times* the teacher faced with Denise (personal communication, October 21, 2012).

The Center provides a place for Denise to belong, but it is not an inclusive school because there are not any students without disabilities. The Center has two community programs every year, but it is unclear how these programs have translated into social inclusion for those students, like Denise, that do not live in close proximity to the school.

**Rights.** Denise's grandmother would prefer Denise to attend a boarding school because she does not feel equipped to educate Denise on Liberian society. When asked about sending Denise to a boarding school, she stated, "Yea, we prefer that. I think for them to sleep there and people to take care of them. I prefer it because they will pick-up and they will train them. I don't have the strategy, they know it" (personal communication, December 13, 2012). However, she was against parents abandoning children there; she stated, "...you don't abandon your child. God will still punish you for it" (personal communication, December 13, 2012).

### **Mary**

Mary returned to the Center, after a long absence, in late November. Mary grew up very close to the Center, but her father got a job a few months before the new school year and her mother, father and Mary moved to the southern part of Liberia. Mary's sister and brother stayed in Paynesville until Mary's return in late November. Mary returned to the Center after her father could not find an adequate school for her in Maryland County; in fact, he could not find a school that would accept her at all. David was told that, "the company [for whom Mary's father is working] have a school, but there wasn't any school there for Mary, I think, they tried, but it wasn't working" (personal communication, December 10, 2012). She lives with her brother and sister very close to the Center. I had

the opportunity to interview Mary's sister and two community members that have lived next to Mary most of her life. I call them Sister's friend #1 and Sister's friend #2.

Mary is about 8 and is a quiet young girl that likes to dance and sing. She practices her ABC's and is learning how to write her name. She has been attending the Center for one year and is in the lower class. Doctors told Mary's mother that she suffered some kind of brain injury (personal communication, December 10, 2012). It is unclear what caused the injury. I was not around Mary much, but it seems she has slow processing and has difficulty retaining information. Some neighbors urged Mary's mother to throw her away. Her sister recalled that some community members, "...said that we should give her away, some say, all type of things, they say how she should die, some she throw her on the dump piles" (personal communication, December 10, 2012). Luckily, Mary's mother and father care deeply for her, chose to value their child, and sought help through family, friends and the Center. Today, Mary lives with her sister and, according to her sister, is happy to be back with her friends at the Center (personal communication, December 10, 2012).

**Emotional well-being.** Mary appeared to be very happy to return to the Center. All the children were very happy to see her. When I arrived that day, Mary was already there and Zack greeted me at the car with Mary in tow and introduced me. The other students pointed and they all had smiles on their faces, including Mary. Mary's sister said that, "she loves the school" (personal communication, December 10, 2012).

Mary's sister suggested that the Center has helped her and her family better understand Mary's emotional state, when asked how the Center has helped her understand Mary, she responded,

We understanding her, something that can make her vexed, she didn't like for people to shout at her, talk at her when get vexed, even when you are forcing her to do things, what she don't want to do, when she get up in the morning, if she doesn't want to go to school, she doesn't like for you to force her. We beg her, we make her to understand, you know in a way that will make her happy, but if you force her she can get vexed that whole day. (personal communication, December 10, 2012)

I never observed Mary upset at the school. She seemed very happy and she smiled a lot. It appears that the Center has positively influenced Mary's emotional well-being based on comments from her sister, friends and observations.

**Inter-personal relations.** According to her sister, Mary's family loves her, especially her father. She said, "The mother she love the child and the father mainly, at the most he love his daughter" (personal communication, December 10, 2012). However, when the doctors diagnosed Mary with a brain injury, her sister recalled that the family felt that, "she couldn't be nobody. Everybody felt discouraged, they said she couldn't be someone good because her way of doing things, it was not looking normal, at least for now, you can understand her, at least" (personal communication, December 10, 2012). Some community members suggested that the family leave Mary on a trash dump or to give her away (personal communication, December 10, 2012).

Mary is not allowed to wander the community alone and spends most of her time with her brother, but when she is upset, she will wander off, so her brother keeps a close eye on her (personal communication, December 10, 2012). Mary's sister did say that she has friends around the community, but Sister's friend #1 feared that, "As time go by, this one grow up to be someone better, they will not look at her again" (personal communication, December 10, 2012).

At the Center, I observed Mary holding hands with many of the students. In the short time she was there before I left, she spent most of her time with either Denise or Zack. It appears that the Center has positively influenced Mary's inter-personal relationships by providing a place to make friends and spend time during the day. The Center does not have an explicit policy or curriculum on developing inter-personal skills.

**Material well-being.** Mary's sister is concerned for her future. She hopes, "that she will become somebody, she improve more than that" (personal communication, December 10, 2012). Mary's sister also stated that if Mary did not improve, she would not have any opportunities in Liberia. Sister's friend #1 stated, "It all depends if she had been to school or a trade, so if they have a school for trade for them, she got the opportunity to have a job" (personal communication, December 10, 2012). Mary's disability will more than likely prevent her obtaining employment in the future because she has a traumatic brain injury, which has limited her speech and language abilities.

It is unclear if Mary will marry and have a family, but Sister's friend #2 expressed a hope when she stated, "By the grace of God, she might someone to love her for who she

is” (personal communication, December 10, 2012). This was a common desire for many of the parents. David suggested that to be truly Liberian, a person needs to have a child.

**Personal development.** Mary became sick when she was about a month old. Her sister recalled,

...she was born, she was born normal, when you see you, you admire her, but at the age of one month...she fell sick and they rush her to the hospital, fever, something like that, from there, she was alright until, her one years old we started noticing a problem on her, she couldn’t talk, she couldn’t talk, nothing she could do for people to understand. She was at the age of four to five years, she started walking, she couldn’t walk good. People here said she could be crippled, otherwise it was hard to say, but by the grace of God, she was not walking normal, but for now at least she gonna be alright. (personal communication, December 10, 2012)

Mary’s sister is the person who suggested her mother and father send her back to Paynesville from the southern region of Liberia when it was clear that there were not any educational opportunities for Mary (personal communication, December 10, 2012). When asked what she thought of the school, Mary’s sister responded,

It is good because it is helping her to know some many things. First she never used to understand anything, you talk she couldn’t reply, but now anything you saying she can talk to you back, you understand her, what she trying to say. (personal communication, December 10, 2012)

Mary's sister attributes Mary's improvement in communication to the Center. Mary's sister continued, "She learned how to talk good and she learning how to sing, at least the ABC's she can try [because of the Center]" (personal communication, December 10, 2012). Mary's sister believes that the Center has made a difference in Mary (personal communication, December 10, 2012).

**Physical well-being.** Mary's family takes care of her, she appears to be well fed and her sister did not mention any specific fears about her physical well-being. Mary's brother does have to be her with all the time, as mentioned earlier, because Mary will wander into the street. Mary's mother and father did take her to hospitals when she was younger, but now her mother takes her to churches. Sister's friend #1 stated, "On her ma's side, they carry her from church to church. She is seriously God woman" (personal communication, December 10, 2012). This is another example of religion playing a major role in the lives of many of the families.

**Self-determination.** Mary does not buy things, such as candy or snacks, as many of the other children do. Mary's sister said that Mary's brother would take care of her if she needs anything throughout the day (personal communication, December 10, 2012). Mary is also not allowed to cook. Her sister said that she does not want Mary to be around the fire because of her disability, but when Mary turns 12, she will try to teach Mary to cook.

**Social inclusion.** Although the Center and her family accept her, Mary is not fully included in the local community, Mary's sister stated, "Other people, some treat her good, some like her, some look down upon her. Thinking she will not be someone good,



she will not be useful, like other children” (personal communication, December 10, 2012). Sister’s friend #2 recalled, “When she was even on the ground for that four years, she never have friend. She started walking before she started having friends” (personal communication, December 10, 2012) and Sister’s friend #1 pointed out, “Nothing, except for the immediate family who would come around” (personal communication, December 10, 2012) when asked if people talked to her when she was not able to walk. Sister’s friend #1 reminded me that, “In the African setting they will look at to be something like a witch” (personal communication, December 10, 2012), and continued, “I don’t think that the parents see it that way. They just are accepting her. When the mother took her to the hospital and the doctor told her it was brain damage, they just accepted her” (personal communication, December 10, 2012). As Mary has grown, she has gained more acceptance and acknowledgement by her family. The Center has helped by teaching Mary various things, like better communication skills and the alphabet, which have helped her to become more socially included in her family setting. Mary was also the runner up in the Queen contest the prior year. It is unclear how the Center helped to influence Mary’s social inclusion in the community.

**Rights.** Mary’s sister believes that Mary has a right to go to school, but does not think she should attend a boarding school because, “For now, her condition, it is not for the boarding school because she can’t keep conversation well with people” (personal communication, December 10, 2012). Sister’s friend #1 did not feel that children with disabilities should attend a school with their non-disabled peers and stated, “I prefer them having a school for them, instead of them going to the other” (personal communication, December 10, 2012) and Sister’s friend #2 finished her sentence when she stated,

“because the other children will make them to feel bad and they will not want to accept them” (personal communication, December 10, 2012).

### **Chapter Summary**

The Center provides a space for the students to be themselves. The purpose of this chapter was to present the lives of the students and their families and provide a rich, thick description of the challenges and success of each of the students and their families. The caregivers appeared open and honest in the needs of their children with disabilities.

## **Chapter Six**

### **Analysis on the Center and the Quality of Life of the Students**

QOL research can use participant opinion data, such as the participant's thoughts on his or her quality of life and data obtained through the global sources, like the UN or the specific government. Both forms of data contain biases; however, when brought together the two data sets can present a picture of a person's understanding and acceptance of his or her life and the state of the country. Deneulin and McGregor (2010) reminded readers of the psychological happiness one can feel in a given situation, but happiness to a subjective measure. A person can be happy without running water, but his or her quality of life could improve with it. In subjective well-being theory, a participant's subjective well-being is determined in terms of life satisfaction and hedonic level (Diener, 1994). Social indicators, although not completely objective, are used to determine a country's QOL (Diener & Suh, 1997). Individual data help to examine each family's life, while national data helps to place those opinions in a context.

In this research, I use Schalock and Keith's (2000) QOL Framework to determine a participants' quality of life based on participant responses within eight domains:

1. emotional well-being
2. interpersonal relationships
3. material well-being
4. personal development
5. physical well-being
6. self-determination
7. social inclusion
8. rights. (p. 333)

Further, Sen's (1999) capabilities approach uses data to discuss the capabilities people have within a country. Capability is "the substantive freedom to achieve alternative

functioning combinations (or...the freedom to achieve various lifestyles)” (Sen, 1999, p. 75). In Table 7, I identify the level of influence using a five-point scale with 0 representing “not influential,” 1 representing “slightly influential,” 2 representing “somewhat influential,” 3 representing “influential,” and 4 representing “extremely influential.” I also include the mean and standard deviation for each of the domains and families. Following Table 7, I combined the participants’ answers to questions based on the domains with national data to place the participant answer in the Liberian context for further analysis.

**Table 7: Rating Scale for the Level of Influence**

Students' Families	QOL domains								<i>M</i>	<i>SD</i>
	Emotional well-being	Inter-personal relations	Material well-being	Personal development	Physical well-being	Self-determination	Social inclusion	Rights		
Adam's Family	4	1	4	4	2	1	2	1	2.38	(1.41)
Zack's Family	4	4	4	4	3	1	3	1	3.13	(1.13)
Patricia's Family	4	1	1	3	2	1	2	1	1.88	(1.13)
Andrea's Family	4	1	1	3	3	2	2	1	2.13	(1.13)
Alexis's Family	4	1	1	3	3	1	2	1	2.00	(1.20)
Kevin's Family	4	1	1	3	1	1	2	1	1.75	(1.16)
Joseph's Family	4	4	1	2	3	1	2	1	2.25	(1.28)
Terri's Family	4	3	1	3	3	1	2	1	2.25	(1.16)
Denise's Family	3	1	1	2	3	1	2	1	1.75	(0.89)
Mary's Family	4	3	1	2	3	2	2	1	2.25	(1.04)
<i>M</i>	3.90	2.00	1.80	2.90	2.60	1.12	2.10	1.00	2.18	
<i>SD</i>	(0.32)	(1.33)	(1.32)	(0.74)	(0.70)	(0.42)	(0.37)	(0.00)		

### Emotional Well-Being: Safety, Spirituality, and Happiness

According to all the caregivers, the Center is influential in adding to the emotional well-being of all the families. Of all the QOL dimensions, it received the highest ratings for all families ( $M=3.90$ ,  $SD=0.32$ ). In my observations, I did not observe any event that would cause me to disagree with the participants' statements. The Center appeared to influence Denise's family slightly less than other families, receiving an average rating of 1.75, compared to the overall mean of 2.18 for all families. Denise's grandparents mentioned that Denise had more positive interactions with them since attending the Center, but they seemed to be more hopeful that God would intervene more than other families. This could be because Denise's grandparents appeared much older than the other parents or perhaps her family was more religious. The reason is unclear. All the other students showed a more clear influence in the domain of emotional well-being. Terri, who Patricia described as *crabby*, laughed and smiled. Terri's mother recalled that Terri was very disrespectful to her stepfather; however, after attending the Center her demeanor towards him began to change. Terri's mother appeared to be happy about this change and mentioned it specifically when asked how the Center has helped Terri. The Center's apparent positive influence in her emotional well-being seems to have affected her relationship with her mother and stepfather in a positive way. Joseph's mother expressed great appreciation to the Center because she is able to have a little time to herself and her business while Joseph is at school. At the PTA meeting, all of the parents expressed an appreciation for the Center and stated that the Center has had a positive impact on their families. An INGO and government official also agreed that Center has had a positive effect on the families. One employee from an American Center stated, "Yes, I think on the whole the children and their families affiliated with [the Center] are

much better off than children with disabilities unable to go to school or in residential facilities” (personal communication, November 13, 2012). A government official aware of the Center stated, “...the best part of what they do is the individualized work and that has to count a lot for something, I don’t know the whole program, but for what I have seen, I’ll put my money on attention that each child gets...” (personal communication, November 27, 2012). All of the students have at least one family member that cares for their well-being. Unfortunately, all of the students have been discriminated against outside the Center. The Center provides a sense of safety and well-being for all the students and their families, a place to belong in a country that consistently excludes them.

A faith in a god was a theme found throughout the interviews. Each of the parents discussed the role of a god in their lives as a coping mechanism when dealing with difficult situations that arise with their child with a disability. Religion plays a role in the Center’s day-to-day activities as well. The upper class learned how to sign *church* and *God loves you*, which they signed to me at least once a day. The Center does not advocate one religion over another and will accept all religions; however, there is a prayer session every morning with a Christian focus, as they prayed to *God* and *Jesus*. Two of the families are Muslim. Since the students attend school on Fridays, they do not attend their local mosque. Religion appears to be an important part of most Liberians’ lives. For the families at the Center, it seemed to offer a sense of hope that things would get better with that belief.

In order to see the impact of the Center on the influence of the emotional well-being of the families, it is important to revisit Liberia’s current situation to place these findings in a context. There appears to be little research on the effects of the war on the

Liberian population; however, violence at any level has detrimental effects on a person. Jakupcak *et al.* (2007) found that Iraq and Afghanistan war veterans diagnosed with post-traumatic stress disorder (PTSD) were more likely to exhibit hostile and aggressive behaviors than those Iraq and Afghanistan war veterans without PTSD. None of the students at the Center are old enough to have experienced the violence firsthand; however, all the caregivers either stayed through the violence or fled to a refugee camp. I only found references to a study conducted by the Carter Center on the emotional effects of the war and the Liberian psychological response. It is not hard to make the connection between a violent civil war and the devastating effects that has on the emotional state of Liberians. The Carter Center (n.d) reported that 50 to 70 percent of females were sexually assaulted during the conflict, 44 percent of ex-combatants have PTSD, 40 percent have major depression and 11 percent have contemplated suicide. One woman working on issues of mental health stated that depression affected about 40 percent of the population (personal communication, November 13, 2012). None of the parents discussed their lives during the war or whether or not they felt depressed; however, it is clear from observations and interviews that the Center has helped them find a place of belonging, support, and love.

One's emotional well being is very much connected to one's desire and ability to survive. Most people can agree that a severely depressed person or a person suffering from PTSD is more likely to commit suicide or cause harm to others than someone that does not suffer from mental health ailments. The Carter Center (n.d) study shows that many Liberians face emotional challenges with very few mental health care workers. The families at the Center face the same difficulties with access to mental health programs



and medication that other non-disabled Liberians face, thus their access healthcare is about the same. However, the Center provides a warm, embracing community that is not only beneficial for the students' emotional well-being, but also for the caregivers. David and Praise work closely with the parents to teach them how to love and care for their child. This appears, from observations and conversations, to have helped deepen (or create) a connection between the student and his or her caregiver. The child with the disability appears to become more human to the caregiver. One example is Zack. His father was very surprised to learn that Zack was able to count or write. His father found hope in those achievements. These small achievements help to strengthen the bond between the parents and their children with disabilities.

### **Personal Development: Education, Skills, and Fulfillment.**

All the parents stated that the Center helps in personal development in some way. For the students, personal development was discussed in terms of educational attainment, for example, the alphabet, how to write, how to brush their teeth, how to count, etc. For the parents, this appeared to mean the personal development in the understanding of disability. The domain of personal development varied across students ranging from extremely influential to somewhat influential. It received the second highest rating in terms of influence ( $M=2.90$ ,  $SD=0.74$ ). One of the goals for the Center is to increase understanding of parents and many of the parents stated that the Center helped them to better understand their son or daughter. The goal is to teach the children a very basic level of education, which is achieved for the upper class. The students in the lower class do not receive a consistent education. This is not to say that Center does not influence their personal development, but the Center does not have the training to teach beyond the

alphabet or song to children with severe cognitive differences. Praise and the ASL teacher, Andrew, are the only two people at the Center with training in education. Praise was trained to teach pre-school and kindergarten and Andrew was trained to teach ASL, although neither stated where they were trained. This has led to some people in the development community familiar with the Center questioning the Center's influence. An employee of an NGO stated,

I don't know whether a child going there with the existing facility and the existing services is changing radically his expectation about life, even basic things, like life and nutrition or not to say socialization, not to say cognitive development, not to say opportunities to find integration in this productive way. I wonder whether [the Center] will have any impact in this, if you ask me sincerely, I would say no.  
(personal communication, November 13, 2012)

I found some of the NGO employee's statements to be corroborated with observation, such as the lack of influence in cognitive development for some of the students.

However, I would say that the Center does add to the personal development of social skills more than children with disabilities who do not attend the Center, such as the development of social skills of interacting with non-disabled adults who value them and the development of social skills with other children with disabilities. Many Liberians with disabilities, especially children, do not have the opportunities to develop those social skills.

### **Physical Well-Being: Health, Nutrition, Recreation, and Mobility**

The Center adds to the physical well being for a majority of the families. The domain of physical well-being ranked third among the Center's influence on the students ( $M=2.60$ ,  $SD=0.70$ ). For the families, physical well-being is tied to what the Center has taught the families about living with a child with a disability. David stated that he has spoken with the families about how to care and love their children. Many parents stated that the Center helped them to understand their child a little more, which might have an impact on how their child is treated at home. This would connect to the physical well-being in the home.

Physical well-being is also tied to students on an individual level because of safety concerns many of the families discussed. Many of the students are not safe in parts of the community. Zack's father feared for Zack's safety daily before Zack began attending the Center. This was because Zack was attacked in the past and his shoes and walking stick were stolen. Zack might have been a target because his disability manifests itself both physically and cognitively. When a student's disability manifests itself both physically and cognitively, the student could become more of a target for violent crimes possibly because they are not able to move as quickly as his or her attackers and the student might not be able to communicate well enough to implicate the perpetrator. When discussing incidents of violence against deaf students, one interviewee stated that police would not even try to find the perpetrators of violent acts against people who were unable to verbally communicate (personal communication, November 21, 2012) Zack's father stated that as long as he was at the Center, Zack's father did not worry about Zack. The Center provides a space where parents can leave their children and feel safe that their children will not be abused, neglected, or left to wander.

Placing the Center in the context of Liberia will help to develop a better description of how the Center helps the families. Liberia is one of the poorest countries in the world and the life expectancy is approximately 58 years (C.I.A, n.d). Sen (1999) stated that the most basic freedom is, “the ability to survive rather than succumb to premature mortality” (p. 24). The health of the country is poor due to the war, underdeveloped infrastructure, and lack of access to reliable clean water and food sources. David told me that many families do not consider children to be *real people* before the age of five because of the high infant/child mortality rate. Children are lucky to make it to the age of five. This is supported by the UNICEF (2012) statement, “Liberia’s infant and under-5 mortality rates remain among the five highest in the world. More than 15 per cent of children die before reaching their first birthday.” In terms of the capabilities approach, many Liberians do not have the basic freedom to survive beyond the age of five. The ability to move beyond that most basic freedom is hampered by the many *unfreedoms*, such as undernourishment, access to health care, sanitary conditions or clean water (Sen, 1999, p. 15) in Liberia.

When compared to Liberia as a whole, the families have a higher level of support from the Center. The Center will not increase the likelihood that these children will live longer, but it does offer one meal a day, and sometimes a snack, as well as access to clean water. The meal usually contains a protein and rice. These things do improve the physical well-being of the students, but the students are still part of a society with a low life expectancy and high incidence of infant and childhood mortality.

### **Social Inclusion: Acceptance, Status, Supports, and Work**

The Center's influence in social inclusion was somewhat influential for most of the families and influential for Zack's family. The domain of social inclusion ranked fourth highest in terms of influence of the Center over the families ( $M=2.10$ ,  $SD=0.37$ ). Zack's family appears to have benefited slightly more than the rest of the families. I rated this higher for Zack's family because David had stated that community members had commented on their surprise to Zack's achievements in school, but he did not state that they commented on other students. I was told that Zack was the most visible child with a disability in the community before the Center opened. This might account for the surprise. Also, Zack was named King for the 2012-2013 academic year at the Center. As stated earlier, this contest is won by having community members place money in a box for each contestant. The person with the most money at the end of the celebration wins the crown. The further social acceptance of Zack could have positive effects on his family's acceptance of him as well. The Center appears to have less of an influence on the other families, although it is still slightly influential because the Center discusses disability rights with other community members.

The Center does not conduct any awareness campaigns or large-scale social inclusion activities outside the immediate community. At the local level, the presence of the Center prompts discussions on disability rights. David and Patricia stated that they have conversations with community members regarding disability, inclusion and rights. Lee (2006) postulated that, "the current disability movement is not just about gaining equality rights for the disabled but also about the fostering of a positive identity, namely, that there is nothing wrong with being disabled" (p. 95). Although the disability rights movement in Liberia is in its infancy, the Center acts an example of how perception on

disability in Liberia could change if given the right focus and attention. David and Praise both discussed their conversations with other community members about the need to recognize people with disabilities as people, period, no qualifiers. This forward thinking has helped the Center gain some acceptance in the surrounding community. At the most basic level of critical disability theory, which is a “new way to conceptualize disability” (Pothier and Devlin, 2006, p. 2), David and Praise are changing the perception in the community of disability. Community members attend events and some are more accepting of the students.

The Center helps people to understand the children. One of the staff members stated that, “Before, I was thinking that they will not come to learn, now, I can see the importance of the bobo” (personal communication, November 9, 2012). This staff member is from an interior county and when she goes home, she stated, “I bring my ID card...the people...ask me ‘where they have this school’ and I say ‘in town’ and they say, ‘the government can bring this school here, we have our children...they are just floating here’” (personal communication, November 9, 2012). There appears to be more acceptance of the Center from my observations of the interactions between the community and the Center’s students and staff; however, I was not able to interview any other community members. In fact, one principal from a nearby school stated that he would agree to an interview, but refused to go through with it for unknown reasons.

The Center’s Anniversary Celebration and end-of-the-year program provide opportunities for the Center to raise awareness. These programs helped students, such as Zack, gain creditability within the community as being a person that can learn. I attended the Center’s Anniversary Celebration and there were approximately 30 to 40 people

watching the events. Although this is small-scale exposure in terms of countrywide, or even citywide, awareness, it is something that was not there for the students before attending the Center.

People with disabilities in Liberia are not socially accepted. There is little action on the national scale to develop an inclusive agenda. They are considered charity cases, in need of assistance and unable to do things on their own. Many of the parents recounted stories of their children walking around and getting money. Praise stated, “When he (Adam) is out there, people ... give him the money ... he goes and buys his fish...and he brings it to put on his boiled rice to eat” (personal communication, December 6, 2012). Andrea’s grandfather equated people loving her in the community with giving her money when he stated, “People love her, people even give her money. Sometimes people can give her 150 [Liberian dollars, about 2 US dollars], when she gets anything she can bring it to us” (personal communication, November 6, 2012). The parents attributed this to their child’s disability. The charity model, specifically for people with disabilities in Liberia, is clear when one walks into *ex-pat*-frequented grocery stores. The only people I observed begging for money outside the grocery stores were people with disabilities. Coleridge (1993) suggested that the charity model for people with disabilities is worse than fascism. He stated,

The “charitable” approach to disabled people is also a form of rejection that is actually more insidious than fascism: it turns disabled people into objects who only receive and who do not participate in the processes, which shape their lives. It sees them as individuals, with individual problems: according to the ‘charity’ approach, if you solve the problems of individual disabled people, then the ‘problem’ of

disability is solved...Except that it isn't. The 'charity' approach is more damaging than rejection as a cause of oppression of disabled people today...with charity the assumption is that 'the problem is taken of'. Out of sight, out of mind... (p. 47)

Coleridge (1993) continued by explaining that when people with disabilities are institutionalized or supported by separate services, there is an expectation that they are well taken care of and that it is OK because *the problem*, the disability, is being taken care of. It places the disability above the person. There is not any focus on the individual as a person with emotional needs and desires to be accepted within a community.

Coleridge's (1993) quotation is applicable to Liberia. As mentioned earlier, many of the parents wanted their children to be separated into boarding schools, asking David and Praise to make the Center a boarding facility. The parents felt that David and Praise were more equipped to take care of their children with disabilities all that time. The separation of parents and child in Liberia is not uncommon. Many children live with family members that have more money, so the children are able to attend school. The point is not that these children would be away from their parents; the point is that these children would be away from everyone, except other people with disabilities. Removing children with disabilities from families or caretakers and placing them in charity-based boarding facilities will not improve the lives of children with disabilities. The charity and boarding school model in Liberia further excludes children with disabilities and in many cases places them in unsafe environments, as was discussed in the early section on boarding facilities.

This charity model connects to ideas within critical disability theory, as well. There is a need to *fix* people with disabilities, so that they can be socially included in the



mainstream Liberian society and fit at or above the cultural *normalcy scale* discussed by Pothier and Devlin (2006). This is seen in many parts of my research, but particularly in the interviews with the parents. All of the parents took their children to spiritual healers to try and attempted to *solve* the problem of disability. I am not trying to blame the parents for their misunderstanding of disability, but show the need for a dialogue and education about people with disabilities.

A few organizations are working to empower people with disabilities and create an inclusive environment. I was able to attend one graduation ceremony of people from a program that taught individuals with and without disabilities a trade, like soap making. The program was only in its second year, but they appear to have done more for the empowerment of people with disabilities than any other organization. Approximately 100 people received certificates at the graduation in different areas, such as skills, adult literacy, community based rehabilitation (CBR) and mental health facilitation. The NGO has held an inclusive teacher-training program that the MOE would not allow public school teachers to attend because the training program occurred during the school day and the MOE would not pay the teachers if they attended the training and missed school (personal communication, November 13, 2012). The country director for this NGO was the most vocal about the lack of assistance from the development community concerning people with disabilities. This participant wanted to know why organizations like UNICEF, Save the Children and other large international organizations, with mandates that include helping the most vulnerable populations, are not placing pressure on the Liberian government to create an inclusive environment. The participant stated, “Why?...It cannot be that the people [employees of these large organizations] are not

attentive or sensitive because among these big organizations, you have qualified people...I am not assuming that they don't have clue. It is much more a political..." (personal communication, November 13, 2012). The question of why these organizations are not supporting projects like this NGO or offering training and support to the Center will be discussed more in the next section on critical disability theory, but when discussing social inclusion it is important to make note that the exclusion of people with disabilities is systemic. The Center faces an uphill battle and with little resources and lack of staff training, the impact on the social inclusion of the students is limited to the surrounding community. Through community programs and conversations, the Center is able to raise awareness, but without an ear in the government, little will change on the national level for these children as they grow up.

### **Inter-Personal Relations: Intimacy, Affection, and Family**

According to the caregivers, the Center's influence in helping to develop inter-personal relationships ranges from slightly influential to extremely influential across the families ( $M=2.00$ ,  $SD = 1.33$ ). Many of the parents stated that the Center provides support and David stated, "We can teach the parents, no matter what, these are your kids, you have to accept them...you have to show them love...and let them feel part of the family..." (personal communication, December 6, 2012). In the memorandum for understanding the parents of each student must sign (see appendix), the Center makes clear that the parent must develop an inter-personal relationship with his or her daughter by, "providing their moral, financial, and spiritual support in promoting, advocating and advancing the well-being of their children and the organization in which you form a part" (see Memorandum for Understanding in the appendix). In some of the families, it was

unclear if the Center aided in the personal relationships in the family or if the relationships were already there before the Center. Adam, Andrea, Alexis, Patricia, Kevin and Denise all appeared to have positive interactions with their direct caregivers before entering the school. Therefore, the Center appears to have the lowest influence in this domain over these families. In addition, all of those students had friends within the community before the Center opened. Zack and Joseph's families appear to have benefited the most from the Center in the domain of inter-personal relations. Zack's father stated that he was more impressed with his son because he did not believe Zack could learn. It appears that because of the Center Zack's father is more accepting of Zack and more confident in his ability to learn. The Center offer's Joseph's mother a daily reprieve from his sometimes difficult behavior and offers Joseph a place to make friends. The Center offers a space for family members to discuss difficulties, although David stated that a support group-like structure is not common in Liberia.

Placing the Center in the context of Liberia, readers are reminded that many children with disabilities in Liberia are more likely to be excluded from the family. Many Liberian children with disabilities are more likely to be physically and emotionally abused, neglected, or abandoned. This was evident in the School for the Blind where parents do not collect their children during breaks. It was also evident in a foster home/orphanage where many of the children had disabilities. Children with disabilities are often stigmatized and considered sub-human. Goffman (1963) stated, "By definition...we believe the person with stigma is not quite human" (Kindle version, location 117 of 2700), not accepted by the mainstream.

The emphasis the Center places on the family is important when children with disabilities around Liberia are being neglected. The Center offers a caring environment and fulfills the very basic needs for the students during the day. This gives the parents time to work, find food or shelter and in an attempt to fulfill the most basic needs. Coleridge (1993) pointed out, "...in the absence of any other services, the main source of learning, support, and help for the disabled child [is the family]" (p. 87). However, in lower income countries, Coleridge (1993) reminded readers that finding the source of learning, support and help a child with a disabilities might need is difficult because, "absolute poverty concentrates the mind on the absolute essentials" (p. 87). This connects to Maslow's Hierarchy of Needs<sup>9</sup> (1943) because many of the families in Liberia do not have adequate food, shelter or safety. Looking at human motivation, Maslow (1943) posited that there were eight domains of human needs. Beginning with the most basic level need: physiological (hunger, thirst, bodily comforts, etc.) and that without meeting those needs an individual would not be able to grow to the high levels, such as self-actualization (Huitt, 2007). Many families must spend a majority of time and energy devoted to developing the physiological and safety levels at the bottom of Maslow's pyramid. The Center offers support and help for families with children with disabilities. David and Praise also encourage the parents to love their children and provide support to both the student and parent when needed. The Center has influenced the inter-personal relationship of each of the families to varying degrees.

### **Material Well-Being: Ownership, Financial Security, and Food**

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<sup>9</sup> Maslow's Hierarchy of Needs includes: Physiological (hunger, thirst, bodily comfort), safety/security, belongingness and love, esteem, cognitive, aesthetic, self-actualization, and self-transcendence.

The dimension of material well-being varied across families, from extremely influential to slightly influential ( $M=1.80$ ,  $SD = 1.32$ ). Many of the caregivers stated that the Center was influential in adding to the material well-being of the families. The Center has the highest influence for Adam's family and Zack's family because they benefit financially from the Center. Adam's parents run the Center, which provides a small stipend. The Center paid Zack's father to build desks and chairs for the classrooms. David stated that his blood relatives were very upset that he offered the job to Zack's father before offering it to one of them. David said he knew Zack's father needed the money more than his extended family, so he was willing to give the job to Zack's father, even though his relatives were upset. This is one of the ways the Center was influential in Zack's family and evidence of the Center's extreme influence in Zack's family life. Many of my observations were based on the daily activities of the Center in providing basic needs for the students, like food and a uniform. This helped the entire family because the family does not have to provide a meal for the student during the school day. Those with only a slight influence from the Center appeared to receive only food and a uniform.

The material well-being of many Liberians could be viewed as low with approximately 84 percent of Liberians being multi-dimensionally poor. Placing the Center in this context helps to understand better the influence the Center might have on a daily basis and for the future. It is unclear the percentage of Liberians with disabilities who are multi-dimensionally poor, but based upon research in other countries (Kuklys, 2005; Mont & Viet Cuong, 2011), it can be conceived that Liberians with disabilities have a larger percentage of their total population who are multi-dimensionally poor. Sen (1999) conceived poverty as a capability deprivation. He stated, "poverty [is] seen as the

deprivation of basic capabilities...” (p. 87). People with disabilities in Liberia have little access to opportunities that would lead to employment, financial or food security. Their capabilities to achieve the desired material well-being are decreased by multi-dimensional poverty. Sen (1999) furthered his argument to say that people with disabilities are further handicapped in their capabilities to achieve material well-being because it is harder to get a job and when employment is secured, it is more difficult to turn that income into capabilities because they need more income to maintain the same quality of life as someone without a disability. Sen (1999) referred to the concept as the “handicap conversion,” which is, “the difficulty in converting incomes and resources into good living, precisely because of disability” (p. 258). There are not any studies conducted on people with disabilities in Liberia, but it is not hard to conclude that the capabilities of these individuals are low.

When one thinks about the future for these the families, it is harder to determine influence. Many of families spoke of hope for the future, but none were able to articulate exactly what that meant. The Center does contribute to the students’ knowledge, skills, and social capital, which Bourdieu (1986) referred to as, “the aggregate of the actual...resources which are linked to possession of a durable network of...institutionalized relationships...” (p. 51). These families could benefit from those interactions. Unfortunately, it is unclear how that knowledge, skills and social capital will translate in the future. One government official stated,

I wish we had the institution where we would augment the education so they get more training, specialized training for what they do, saying that I think, what they have brought from when they came from Ghana and what they have picked up

over the years through the small seminars that they do, they have done a good job.  
(personal communication, November 27, 2012)

An employee of an American Center in Liberia stated,

I am less optimistic that the immediate future will change for children with disabilities but think over time if the international donors that signed on the Convention were less spineless and more willing to hold us accountable for the human rights of individuals with disabilities, we would see changes in a positive direction. If there is no premium put on the importance of protecting the rights of children with disabilities, progress will be much slower. (personal communication, November 12, 2012)

The Center introduces students to many different international NGOs and the former national director of special education was a member of the Center's board. These connections could help the families in the future, but it is still unclear if they will be better off than their disabled peers not attending the Center. Unfortunately, as Sen (2009) pointed out, "People with physical or mental disability are not only among the most deprived human beings in the world, they are also, frequently enough, the most neglected" (p. 258). The prospects that these children will increase their capabilities and rise out of poverty are low. The future of the students at the Center is not likely to be very different for other children with disabilities if there is not a focus on vocational training or an increase in collaborations with local and international NGOs. In addition, there will be little change without a positive societal shift towards people with disabilities. In the lens of critical disability theory, these students are seen as less than human, *dis-citizens*. The

future of *dis-citizen* in Liberia is not hard to imagine considering the current treatment by the country. For those families with children with non-cognitive disabilities, the basic education provided by the Center might help in job prospects, but given the climate towards people with disabilities in Liberia, I am still not optimistic that an employer would be willing to hire them if they were competing for a job against their able-bodied peers.



### **Self-Determination: Autonomy, Choices, and Decisions**

Self-determination is ranked as the second to lowest among the domains ( $M=1.12$ ,  $SD=0.42$ ). Theories in self-determination and motivation take the idea of self-determination past choice to focusing on specific, “factors that nurture the innate human potentials entailed in growth, integration, and well-being, and to explore the processes and conditions that foster the healthy development and effective functioning of individuals, groups, and communities” (Ryan & Deci, 2000, p. 74). One of the most widely used theories of motivation in education is Maslow’s (1943) Hierarchy of Needs described earlier. The students appear to have all their basic needs met with the Center and are able to learn and retain certain things, such as the alphabet and/or numbers. Although the students are not self-actualizing on a theoretical level, their ability to participate in a classroom setting is evidence that they are able to move beyond the basic physiological needs laid out by Maslow (1943). For example, Zack recited the alphabet and community members commented that they did not know he was capable of that. Both Andrea’s and Mary’s family rated slightly higher in the domain of self-determination because their families chose to relocate because of the Center. The Center provides the basic needs of food, shelter and safety throughout the day, which helps the students to focus on their education.

Poverty limits one’s capabilities (Sen, 1999). Liberia is one of the poorest countries in the world with, as stated earlier, a multidimensional poverty rate of 84 percent. The capabilities, in terms of Sen’s definition, of Liberians are hindered because of the high rates of poverty. Sen’s (1999) view on poverty and capabilities looks at the *ends* (things that people would like to pursue) over the *means* (low income). With this

focus on the *ends*, poverty becomes an examination in self-determination and choice; what do people want and what motivates them to get it. The basic needs of many Liberians are not met, so the motivation to grow has been delayed because people are focused on food and shelter.

Poverty hampers the capabilities of people. Sen (1999) refers to this as “poverty as capabilities deprivation” (p. 87). Poverty reduces a person’s ability for growth and development that lead to increased motivation. The need for basic survival items, such as food, shelter and clean water, undermines a person’s ability for self-motivation. This is not to say that countries, like Liberia, do not have self-motivated people who are able to end the cycle of poverty, but that it is less likely that a person will become self-motivated to do more than find food or shelter because basic physiological needs are not met. Maslow (1943) stated,

What this means specifically is, that in the human being who is missing everything in life in an extreme fashion, it is most likely that the major motivation would be the physiological needs rather than any others. A person who is lacking food, safety, love, and esteem would most probably hunger for food more strongly than anything else. (p. 373)

Connecting these ideas to the Center is not difficult. All of the students at the Center experience multidimensional poverty, they do not have adequate access to health care, education and have a low standard of living. All of these factors hinder their abilities to motivate past the basic needs in Maslow’s hierarchy of needs. When the parents of these student’s stated that they would like to send their children to boarding

school because boarding school would take better care of them, they were talking about the basic needs of food, shelter, and clean water, all of which the Center provides. This is an example of the families' basic physiological needs not being met and the motivation to meet them is so strong that the desire to have their children outweighs the understanding that they need their basic needs met. The Center is attempting to supersede those basic needs and motivate these parents to grow past the basic needs to the needs of love and belonging. The students with cognitive disabilities will not be accepted in a boarding school, because most of the boarding schools only accept students with either a hearing or visual impairment. At the Center, the students with hearing impairments have more options; yet, the parents do not send their children to these boarding facilities. This seems to suggest that the Center has been able to improve the motivation of the parents to see past the basic physiological needs and, at some level, understand that their children desire love and belonging.

### **Rights: Privacy, Voting, and Access**

The QOL domain of rights is the lowest ranked among the domains ( $M=1.00$ ,  $SD=0.00$ ). The impact on the family appears to be the right to education for a child with a disability, which is denied under the current law. The Center has not done any work on rights for children with disabilities in Liberia; however, the Center provides a space where children are accepted. This is more than these children have had in the past, outside their immediate family. The Center provides access to an education for all the students. There is variation in the quality of education between the upper and lower class, but the access to an education is influenced because of the Center.

Children with disabilities do not have the same rights as children without disabilities. The current educational law is an example of this, which states, “A school may exempt a child entirely, partially or conditionally from free and compulsory school attendance if it is in the best interest of the child, *especially those with disabilities* [emphasis added]” (ROL Ministry of Education, 2011b). The rights of all children with disabilities are thwarted by this clause, even though Liberia has signed the Convention on the Rights of the Child and the UNCRPD, both of which state that people with disabilities have equal rights to education. This clear violation of the rights of the children with disabilities in Liberia is an indication of the second-citizenship children with disabilities experience in Liberia. Rioux and Valentine (2006) pointed out, “Citizenship grants rights...but also provides access to public goods and services – to work, to education, to technology, and to social protection” (p. 55). Children with disabilities in Liberia do not share the same rights as other Liberians, making them second class citizens and another example of how they are, in Pothier and Devlin’s (2006) word, *dis-citizens*.

Even if the educational clause is changed, many people with disabilities lack access to buildings because of the lack of modifications to building construction. There are few paved roads in the country and I only saw a few sidewalks in the downtown area that were wheelchair accessible. I did not enter any building that had a visible elevator. The Minister of Education moved her offices to a smaller building because she was unable to climb the eight flights of stairs to get to her office (personal communication, November 27, 2012). The Ministry of Education is split between one massive building downtown and a smaller building in Sinkor. The University has the same issue. One student reported seeing another student carried up the stairs because the school does not

have an elevator for a person in a wheelchair to get to the higher floors (personal communication, October 5, 2012). Metts (2004) suggested that Universal Design theory, which points out that buildings made accessible at the beginning stages of development are more cost-effective than adding accessibility features later. These issues of access, at the most basic definition of the word, connect to the idea of rights. People with disabilities in Liberia do not have the right to enter a building. Pothier and Devlin (2006) pointed out, “If the sign says that all are welcome, then gender or race is not an absolute barrier to getting in the door, but a set of stairs is an absolute barrier for a wheelchair user” (p. 12). These absolute barriers impede the rights of Liberians with disabilities to exercise their right to education (although not with the current educational clause) and their right to engage democratically elected government officials in discourse. How are people with disabilities supposed to advocate for themselves when the building is not accessible? Siebers (2008) took the idea of lack of rights and exclusion from society further when he stated, “Disability marks the last frontier of unquestioned inferiority because the preference for able-bodiedness makes it extremely difficult to embrace disabled people and to recognize their unnecessary and violent exclusion from society” (p. 6). The construction of buildings and the explicit prohibiting of children with disabilities from school are just two examples of the, “violent exclusion from society” and the denial of rights people with disabilities face in Liberia.

When discussing the influence of the Center on the rights of its students, the influence, at the most basic level, is clearly there. These students are denied the right to go to school, and the Center is offering an opportunity for an education. Without the Center, these children would be excluded from society even more. Although the Center

does not work directly to increase the rights of these children at the national level, the Center does provide a much-needed service to a group of students denied access to other forms of education.

### **Explanations for the Overall Levels of Influence**

The finding that the average level of the Center's influence varies among families indicates that the Center impacts them differently. Zack's family seems to benefit the most from the Center ( $M=3.13$ ,  $SD=1.13$ ), followed by Adam's family ( $M=2.38$ ,  $SD=1.41$ ). The same average level of influence ( $M=2.25$ ) is exhibited in Joseph's family ( $SD=1.28$ ), Terri's family ( $SD=1.16$ ) and Mary's family ( $SD=1.04$ ). The Center had the next highest level of influence on Andrea's family ( $M=2.13$ ,  $SD=1.13$ ) and then Alexis's family ( $M=2.00$ ,  $SD=1.20$ ). The Center's influence on three families fell below the mid-point score of 2.00: Patricia's ( $M=1.88$ ,  $SD=1.13$ ), Denise's ( $M=1.75$ ,  $SD=0.89$ ) and Kevin's ( $M=1.75$ ,  $SD=1.16$ ). Both Denise and Kevin's families appeared to be the least influenced by the Center.

The families appear to benefit in different ways from the Center. For example, Zack's family appears to have benefited the most and has some of the highest ratings in the domains of emotional well-being, inter-personal relations, material well-being and personal development. Zack's father earns work from the Center. This could increase the likelihood of Zack's father responding more positively to the questions about emotional and material well-being because Zack's family is more financially secure from the work the Center offers him. Zack's father, also stated that he has learned more about his son from the Center, this could affect the family's inter-personal relations, personal

development, and emotional well-being. Another example is Denise's family. Her family is the only participant to not receive an extremely influential rating in any domain. Although her grandparents' stated that they liked the Center and that the Center has had influence on the family, it was unclear how. Her grandparents' spoke more about the hope that God would intervene and less about the Center. This also led to a lower rating in personal development than many of the other families. Both the responses of Kevin and Denise's families indicate the same level of influence, Kevin's experience at the Center appeared to be very different. The difference in the standard deviations indicate that there was more variation in the responses of Kevin's family.. Kevin has epilepsy and a physical disability, but does not have a cognitive disability. He is also able to communicate verbally and appears to be less stigmatized in the community. He did not report any violent acts against him or his family, as many of the other families reported. This could account for the lower average rating on the level of influence for Kevin's family. Another example is Joseph's family. As explained in his profile, Joseph has some very difficult behaviors. The Center offers a reprieve to the family, which appears to positively impact their emotional well-being and inter-personal relations, as stated by Joseph's mother. Each of the families appears to struggle with living with a child with a disability, but the Center seems to have a positive impact across most of the domains for each of the families.

The variation of the Center's influence on each family could also be accounted for by the Center's capacity. David and Praise focus on teaching the parents how to love and care for their children more than focusing on the families' national rights. There appears to be more of a focus on the home, which could account for the overall higher average

level of influence in emotional well-being ( $M=3.90$ ,  $SD=0.32$ ), personal development ( $M=2.90$ ,  $SD=0.74$ ) and physical well-being ( $M=2.60$ ,  $SD=0.70$ ) Many of the parents stated that they had learned something about their child, which gave them hope that their child could “be someone someday.” It was unclear what that meant, but many of the parents spoke about their children having an “office job.” However, the Center does not appear to have the social capital needed to influence in the area of rights ( $M=1.00$ ,  $SD=0.00$ ). David, Praise and many other parents stated that they would like to talk to a government official about the rights of their children, but were unclear how to do that. Self-determination also received a lower average level of influence ( $M=1.12$ ,  $SD=0.42$ ). It was difficult to determine how the Center influenced the families’ self-determination outside of the advice and basic services provided. The Center capacity to influence the families appears to be stronger on the micro over the macro level due to the capacity of the Center.

Although I broke these finding up by individual families, there is a sense of a pattern based on disability. Zack’s and Adam’s families seem to benefit the most and they both have cerebral palsy. In addition, they are the only families who experience a higher level of influence in the domain of material well-being because both families receive income from the Center. The families of Andrea, Alexis and Patricia experience very similar levels of influence across the domains. All three of these children have a hearing impairment. Patricia’s family demonstrated a slightly lower level of influence in the domain of physical well-being because of the tied tongue procedure. The family, especially the mother, did not appear to be interested in the Center’s opinion; however, she was very interested in my personal opinion. This incident led me to place a lower



rating on the Center's influence in physical well-being with regards to Patricia's family. Andrea's family exhibited a higher level of influence in the domain of self-determination because her family moved to the community for the Center.

Although Terri and Kevin experience seizures, the Center's level of influence on the families was different. This might be because their disabilities manifest in different ways. Terri experiences an intellectual disability in addition to seizures, while Kevin appears to have normal cognitive functions. The three families of Terri, Joseph, and Mary exhibited the same average level of influence and they all share in a level of cognitive disability. Kevin is the only student who seemed to be affected by his disability physically, and not both physically and cognitively. This might account for his lack of placement within the pattern. It also might account for his family's lower average level of influence because physical disabilities do not appear to be as stigmatized in Liberia as cognitive disability. Denise's family also, does not appear to fit within the pattern. Denise has a cognitive disability, so the exclusion of Denise's family in the pattern does not appear to be because of her disability. This could be because of unknown influences in her family life outside the Center. All the families experience the Center in different ways, but a pattern appeared to be evident in the data.

The Center is not perfect, but the holistic model used helps both the student and the family. The influence of the Center sets the stage for examining the policies for and practices with people with disabilities in Liberia. Liberian culture regularly shuns families with children with disabilities, but many of the families have found a sense of community. If the Center does influence each of these families, then many other families not associated with the Center could be facing more difficult lives with more

stigmatization or exclusion. The Center is changing the way families think about disability. David's insistence that the Center stay a day school challenges the status quo of removing a child with disabilities from the home and placing him or her in a boarding facility. The Center's forward thinking has made it possible for these children to stay with their families, raise their quality of life, and increase their personal development. The *normalcy bar* for Liberian society does not appear to be changing any time soon, but for these 10 families it has. These children are more accepted within their families and have a sense of belonging when they are at school.

### **Chapter Summary**

This chapter analyzed my findings and compared them to different theories. The QOL framework is the starting point to discuss the lives of children with disabilities in the Liberian context. Amartya Sen's (1999) capabilities approach and Maslow's (1943) hierarchy of needs helped to analyze the ability these families and other Liberians have to change their lives to increase their quality of life on both a physical and psychological level. The analysis of the framework and theories on the families' lives help to determine the influence of the Center.

### **Chapter Seven**

#### **The Part in the Whole: a Critical Discussion on the Issues and Conclusions**

In this qualitative research, I provide a rich analysis of the impact of the Center on the families' quality of life. The Center is located within the context of Liberia, an environment where situations are almost impossible for children with disabilities. This research not only informs readers about the situation of the families studied in this case, but also serves to add to a broader discussion on people with disabilities in Liberia. The lens of critical disability theory is helpful and necessary. It is obvious that policy changes are needed, such as changing many of the cultural stigmas that denigrate, and reforming government policies that exclude children with disabilities.

In this chapter, I will provide an analysis of the challenges the families face to integration in their communities through a critical lens. I provide suggestions on the practical implications of critical disability theory in the Liberian context. I revisit my research question and also provide suggestions on future policy and changes that could be made to the Center. I identify some of the potential contributions to research this study offers, the limitations and suggestions for further study. Finally, I offer concluding remarks.

### **Creating a Critical Context for Change**

In my study, all of those interviewed who work in the development sector stated that people with disabilities are stigmatized and marginalized. All of my interviewees stated that the Liberian government should be doing more for people with disabilities. One of my interviewees who worked for the UN stated that the UN has the resources to help the Liberian government implement a Child Friendly Schools model, but there is a

lack of political will, institutional continuity and understanding of the issues. The UN employee stated,

One big issue is not understanding the [educational issues] and...cognitive ability... The high turnover has been a problem, especially in the [Ministry of Education], we think that this is good and we are moving in this direction, [then] the group is removed and there is new change and you must start from square one... There is no institutional memory... (personal communication, November 20, 2012)

This Center seems to exist because many in the government appear to lack the understanding of the issues surrounding education and disability. People with disabilities seem to be marginalized because there has not been a substantial effort by the government to include those with disabilities in the decision making process. Critical disability theory creates a format for discussion on the lives of people with disabilities.

Critical disability theory is theory that “emerges from the bottom up, from the lived experiences of persons with disabilities, rather than from the top down, from the disembodied ivory tower” (Pothier & Devlin, 2006, p. 9). The inclusion of people with disabilities in the decision making process would be beneficial to creating a more inclusive environment because many people with disabilities understand their needs. The discussion on empowerment and substantive equality for people with disabilities could begin with a conversation on four themes: (1) language, definition, and voice, (2) contextual politics and the politics of responsibility and accountability, (3) philosophical challenges and (4) citizenship/dis-citizenship. These four themes could lead to more

substantive changes in the future development of Liberia to include people with disabilities.

**Language, definition, and voice.** Language, definition and voice in critical disability theory refer to the way people with disabilities are discussed in society. The evolution of language about people with disabilities in many countries has gone from using terms such as *the crippled*, *the handicapped*, *the retarded* to person-first language, *a person with autism*, *a person with a visual impairment*. Liberia still refers to people with disabilities as “bobo” or “the crippled.” The definition of disability varies from society to society. As stated early, many Liberians seem to focus on people with physical disabilities, blindness and deafness and refer to those with cognitive disabilities as “crazy.” In a practical sense for Liberia, the focus should begin with a discussion on the way people refer to people with disabilities. A move away from the current terms of “bobo” and “the crippled” could bring qualities that are more human to those many Liberians deemed sub-human. This could help to create the environment where a critical discussion could take place on the need to move away from the focus on the differences people possess to a discussion about the way society had created the difference.

The mission for NCD, a government organization focusing on policy for people with disabilities, did not include people with cognitive disabilities. Disability was defined as a person who is physically disabled or has a visual or hearing impairment (personal communication, November 15, 2012). This excludes a long a list of other impairments such as cerebral palsy, autism, epilepsy, and intellectual disabilities. Pothier and Devlin (2006) pointed out, “To be a person is to have the capacity to appear on the political radar” (p. 3). People with cognitive disabilities do not even appear on this radar. One

high-level education official stated, “We have those kinds of people in Liberia?” (personal communication, November 28, 2012). This is only one person at the Ministry of Education and this person does not represent the entire Ministry, but it is curious that there is someone at the Ministry of Education with these views. I feel it warrants further investigation into the perception of children with disabilities at the Ministry of Education.

In addition, people from NUOD, a Liberian disability rights organization, and NCD participated in the most recent High Level Panel on the Post 2015 Millennium Development Goals (MGD). Unfortunately, their voices are muted. In the communiqué regarding the panel, the empowerment of girls and women was mentioned, but people with disabilities were not (Communiqué from the Meeting of the High-level Panel of Eminent Persons on the Post-2015 Development Agenda in Monrovia, Liberia, 2013). NUOD and NCD are Liberian organizations that have a mission to promote the rights of people with disabilities, but it appears that their voice is ignored.

The rallying cry of the disability movement, *nothing about us, without us* begins a conversation on voice. People with disabilities often have non-disabled people talk for them. It is important that everyone’s voice be heard. In this study, I had to rely on the voice of the caregiver because most of the students have not developed the ability to speak. For children with moderate to severe disabilities who have difficulties communicating, some researchers suggest that the voice of the child could extend to the family. When discussing access to therapy for children with severe autism in Canada, Baker (2006) stated,

The balance between the individual and social responsibility is realized by defining the right of the child as the right of the family. The characterization of the

family as the holder of the child's civil rights is not unique to children with disabilities. However, the role that must be played in the exercise of this right is often more demanding for the parents of children with disabilities. (p. 184)

This is not to say that the child is without a voice. Children with disabilities, even severe, should be encouraged to participate to the extent possible to create a life of meaning to them. This requires an understanding that even people with severe disabilities have the capacity to make decisions in their lives. In the context of Liberia, this would likely begin with the empowerment of the caregiver to teach their child empowerment to their level. Wehmeyer (2005) suggested, For people with severe disabilities, limitations in personal ability, opportunities, the perceptions of others, and the environments in which they live, learn, work, or play limit the degree to which they can become more self-determined. The role of teachers is not to teach students to control their lives. It is to enable students with severe disabilities to become more self-determined, even if it is just a little bit more. (p. 119)

I would extend this to include the parent, especially in Liberia. Empowerment programs for parents of children with disabilities could be important to help the caregiver develop a voice and the needed vocabulary to advocate for the empowerment and substantive freedoms for their children when their children are unable to communicate their needs or desires.

**Contextual politics and the politics of responsibility and accountability.** The purpose of critical disability theory is to create a space for empowerment. This research has shown that these families would like to have a space for dialogue. Many of the

participants stated that they would like to talk to people in the government, but they did not feel the government would listen. Critical disability theory seeks substantive equality where differences are taken into account, but does not place blame of difference on anyone. Disability is everyone's responsibility. Society should be held accountable for creating a space for disability. In post-conflict countries with outside development agencies present, the responsibility falls on them as much as anyone else in the society to hold the government and other stakeholders accountable to include people with disabilities in the discussion on development. Development agencies should hold the government accountable in creating inclusive legislation.

Many of the interviewees from development agencies were disappointed by the lack of interest on inclusive policies from the government and seemed to think the lack of political will was to blame, even though the Government of Liberia signed the UNCRPD and the CRC. As this research has shown, the responsibility for these children with disabilities has fallen on the shoulders of the family members or caregivers. Blame is placed on the family or person with a disability for having the disability. Many people with disabilities are considered a charity case by most. Many of my Liberian participants commented on the need to *cater* to people with disabilities. A dialogue of empowerment is seen in some circles, such as the INGOs that focus on disability, but even the Liberian NGOs still believe that people with disabilities need to be taken care of.

Some people question Liberia's ability to address the needs of people with disabilities when the entire population is multi-dimensionally poor. This is an important question. Many of my interviewees did not appear to expect that all of the needs of children with disabilities would be addressed overnight, but they did express a desire that



their families needs to be a part of the development conversation, their children be included in the school system, and be accepted by their communities. My interviewee from the UN agency stated that the former two requests were achievable and research has shown that when teachers are trained to teach children with disabilities and children with disabilities are included in the classroom, communities are more likely to accept them (Johnstone & Chapman, 2009; Lewis, 2009).

**Philosophical challenges.** One of the greatest challenges facing people with disabilities is society's idea of disability. Pothier and Devlin (2006) pointed out, "Persons with disabilities may experience functional limitations that non-disabled persons do not experience, but the biggest challenge comes from mainstream society's unwillingness to adapt, transform, and even abandon its 'normal' way of doing things" (p. 13). Societies create a *normalcy bar*. If someone does not meet that bar, then he or she is considered below society. The Liberians *normalcy bar*, as discussed earlier, is someone that can have a job and family. Most people with disabilities fall well below that bar because of societal stigma, lack of educational opportunities and barriers to the labor market. Liberians with disabilities could begin to fit into the ideal *normal*, if they were given access to the tools available to non-disabled people.

Siebers (2008) takes disability to a new philosophical level when he suggested, disability is nearly always interpreted... as a personal tragedy, as inherently individual, and in a manner similar pain. Neither disability nor pain, however, differentiates the individual. They do not for the most part belong to one person alone. They are social inventions, external to people, that mark them as

individual. The dominant social representation of disability... is the individual alone in pain, and it is difficult to find alternative representations, especially those that reveal pain's social origins. What would it mean to conceive of pain not as an individual or private sensation...but as a socially mediated identity...?" (p. 188-189)

Disability is seen in society as pain, both physically and emotionally, because disability is not seen culturally as something to be praised. It is not seen as a difference, but a deficit, a dis-ability, meaning not able, rather than a difference, like being Black or White. In Liberia, many feel sadness when someone has a child with a disability. People feel sorry for the person. When Zack and Adam walk around the community, people give them money, not because they ask for it, but because they are seen as living a painful existence that needs charity to help them achieve in society.

In Liberia, there is a misunderstanding on the ability of difference, especially for those with cognitive disabilities. Liberians believe that people with disabilities are not able to contribute economically and are thus a burden on the family (personal communication, November 8, 2012). One NGO worker stated, "Normally in Liberia, crazy people must be in crazy homes, you know, that is common belief" (personal communication, November 8, 2012). As stated in the previous section, there is a belief that people with disabilities must be *catered* to and that they are not capable of things without the help of someone that is able-bodied. Another NGO worker has a positive look towards the future,

now people are more thinking about empowerment, thinking about education, thinking about economic empowerment and all of these issues, I think that are now being considered, another thing has to do with how we see the issues of people with disabilities as a kind of rights issues and more people will look at it from the perspective of respecting the individual for who they are...  
(personal communication, November 15, 2012)

Although people with cognitive disabilities were not mentioned in the mission for NCD, the organization is trying to correct the original mistake and include those with cognitive disabilities (personal communication, November 15, 2012).

The systematic nature of the inequality towards people with disabilities is seen throughout this research. The government does not create a level playing field where these individuals could become more active members of society because of the philosophical challenges. Unfortunately, without a positive change in societies' view of people with disabilities, there is little chance that creating an inclusive society is an option. The lack of political will, the societal view towards people with disabilities and countless things that need to be put in place to create a functional, growing economy adds to the philosophical challenges facing people with disabilities in Liberia.

**Citizenship/Dis-citizenship.** Pothier and Devlin (2006) coined the term “dis-citizenship” (p. 1) to describe the lives of people with disabilities. Citizenship is more than just a passport or the ability to vote. Citizenship encompasses, “the capacity to participate fully in all the institutions of society – not just those that fit the conventional definitions of the political, but also the social and cultural” (Pothier & Devlin, 2006, p.

1). I would argue that citizenship is at the very essence of identity. When asked, “Who are you?” I respond, “I am Kimberly, I am an American, I am female, etc.” Connection to a country or belonging to a specific social group helps to define one’s identity. People with disabilities are *dis-citizens*; they belong to a negative identity. They are second-class citizens. In Liberia, people with disabilities are not given access to basic things, such as education or the labor market. They also do not have the political power. They are not empowered. The boundaries for citizenship into the Liberian society are messy. The war left many people struggling to regain access to the mainstream society after the atrocities. For example, many former female combatants find it difficult to reach the *normalcy bar*, “the women who went to war are shunned and live in slums, scraping by for survival, often by prostituting themselves for a few dollars” (MacDougall, 2013, para. 21). It is clear that people with disabilities also lie beyond the boundaries. Those with disabilities that have jobs and families are in the national NGO sector working on disability rights. They are making suggestions on inclusive policies that fall on the deaf ears of the Liberian government. I will repeat one participant’s emotionally charged response when asked about the future of people with disabilities in Liberia,

I am less optimistic that the immediate future will change for children with disabilities but think over time if the international donors that signed on the Convention were less spineless and more willing to hold us accountable for the human rights of individuals with disabilities we would see changes in a positive direction. If there is no premium put on the importance of protecting the rights of children with disabilities, progress will be much slower. (personal communication, November 13, 2012)

Liberia's most recent development plan, RISING 2030, seeks to become a middle-income country by 2030 without leaving any Liberian behind, but children with disabilities are being left behind.

### **Practical Implications of the Critical Disability Theory**

Critical disability theory begins with a change in society's opinion of disability. There are many hard-working people in Liberia who focus on changing the perception of disability. These are the beginning steps to change. Critical change does not happen overnight. In the United States, people with disabilities are still fighting for their rights. People with disabilities in the United States did not have access to an education until 1975 with the Education of All Handicapped Children Act and it was not until 1990 that George H. W. Bush signed the Americans with Disabilities Act (ADA) called, "the most sweeping disability rights legislation in history" (Rehabilitation Research & Training Center on Independent Living Management, 2002). Many steps led to the passing of the both of those Acts in the United States. In fact, much of the research around critical disability theory is based in higher income countries like Canada (Pothier & Devlin, 2006) and the United States (Siebers, 2010). This does not mean that Liberia need not include people with disabilities in dialogue on post-conflict reconstruction. This is a new beginning for Liberia. As the PRSP states, "Liberia is on the move. After decades of economic mismanagement and fourteen years of brutal civil war, Liberia's national nightmare is over." Liberia has a chance to begin to make those small steps to include people with disabilities.

### **Summarizing the Study**

This case study examines the influence of an educational center in Monrovia that caters to students with disabilities. Ten families participated in in-depth interviews, home visits, observations and student work review. NGO workers, governmental officials, and development workers were selected because of their knowledge of education and/or disability in Liberia or because of their connection to the Center. These 39 individuals provided immeasurable amounts of information and personal experience to create a detailed picture of life for people with disabilities in Liberia. Through thick, rich description, I presented evidence that the Center does influence the quality of life of these 10 families. I sought to inform our understanding of disabilities in Liberia and explore the need for further research.

### **Revisiting My Research Question and Further Analysis**

My research question is:

Based on caregiver responses, and taking into account the Liberian context, how does The Alliance Center for Children with Disabilities influence the quality of life for its students and the students' families?

This research found that the Center has influenced each family's life in different ways within the domains of the QOL framework. Zack's father does not have to worry that Zack is wandering the community, Alexis's grandfather sees a brighter future for his granddaughter, and Joseph's mother has a daily reprieve from her son's difficult behavior. In addition, the students are getting a social and educational opportunity that would have not otherwise been afforded to them. Throughout the data collection, it was evident that the Center adds something to each of the families' lives. There are not any

other programs in the area and the Ministry of Education does not have a system in place to include these students. The immediate impact is clear: The Center is caring, safe and provides some education to each individual student. The Center offers support for the parents and the student gain a social circle of their peers, providing them with friends and sense of belonging. Mary and Andrea's caretakers moved the girls to the area to attend the Center. Mary's parents moved to the southwestern region of Liberia and when they realized that Mary did not have a school to attend, they moved Mary back to Monrovia to live with her sister. Andrea's grandfather heard of the school and moved to the Paynesville area because he feels strongly that the Center will help Andrea in the future. The Center fills a void of educational opportunities for children with disabilities.

The Center is less influential in the students' collective future or their lives within the communities. The cultural norms pose problems for the Center when trying to influence the community. While discussing Patricia's tongue procedure, David was adamant that the Center would support the mother in her decision and would not comment on his own thoughts in front of her for fear that he would offend the mother and remove Patricia from the program. The Center navigates a fine cultural-political line. It was unclear the boundaries of the line, but David did not want any of the parents to feel as though he was imposing his ideals on them. The navigation of cultural norms and achieving the Center's objectives is a fine line. One objective of the Center is to, "Counsel the families on how to treat the child correctly and include him or her in family activities" (Niapele Project, n.d.-a), yet, the Center was not able to voice its opinion about the procedure. This objective is hard to meet, as well, when there are not any trained staff members in disability education, identification or in the medical field at the Center. This

objective is even harder to achieve because there are few people in the country that fit the description.

The Center's influence shows the need for further inclusion of children with disabilities in policy and discussion on development plans. Each of these families faced hardship because of their children with disabilities, whether that was emotional or financial. For those families not associated with the Center, but who have children with disabilities, the positive influence might be taken away from lack of services and there could be increased challenges because children with disabilities are not seen as complete Liberian citizens. As Pothier and Devlin (2006) pointed out, "...we need new ways to conceptualize the nature of disability, a new understanding of citizenship that encompasses the disabled, new policies to respond to the needs of the disabled, and a new legal vision of the entitlements of the disabled" (p. 2). There is strong societal stigma that limits these students' ability to access any other forms of education, not to mention the legal barring of students with disabilities in the new education law. There is no political will in the government, leaving many people with disabilities to fend for themselves, as stated by many of the participants working in the field. There is still a charity model in Liberia, as seen when the students walk around the community. There is very little empowerment in Liberia for people with disabilities and there is an expectation that they are only able to beg.

Looking at the challenges that the Center faces through a critical disability lens and asking the question, why it is so difficult for the Center to develop a strong connection with the surrounding community and build on relationships with neighboring schools is important to understanding the context of the Center and the impact which it



has already created? The Center is riding upstream against a political system that appears to lack the will to help. Societal norms, superstitions and stigma have it made it very difficult and nearly impossible for the Center to develop meaningful relationships with the surrounding communities. However, through change agents, like David and Praise, the students are safer and more accepted around the Center.

There is little to no community or government outreach to people with disabilities. Many of them will not have the same opportunities as their non-disabled counterparts in terms of job prospects, family life and continued improvement in their quality of life unless the government adds them to the agenda. There is strong evidence from other countries, including high-income countries like the U.K., that people with disabilities are still the poorest of the poor and remain the poorest of the poor. People with disabilities deserve as much consideration in the creation of services as people without disabilities. People with disabilities are citizens of Liberia and should be treated as such.

### **Suggestions to the Center**

The Center provides an invaluable service to the community, through two annual programs, support and encouragement for parents and home visits. Two international NGOs voiced concern about the day-to-day management of the Center. It would be helpful if there were an assistant for the director that could help with paperwork and organization. It would be better for the Center, although unclear if financially feasible, for the director and his family to move to live outside the center. The fact that David and his family live at the Center has caused concern with the property owner (personal

communication, November 21, 2012). It would be helpful if there were more opportunities for trainings for the employees, not only on the various disabilities, but also, in pedagogy. Unfortunately, this is impossible in Liberia because there are not any programs for teachers of students with disabilities.

### **Policy Suggestions**

The most urgent education policy need for children with disabilities in Liberia is the repeal of the clause in the education law that states, “A school may exempt a child entirely, partially or conditionally from free and compulsory school attendance if it is in the best interest of the child, especially those with disabilities” (Republic of Liberia Ministry of Foreign Affairs, 2011). This statement goes against the CRC and the UNCRPD, of which both the Government of Liberia has signed and ratified. It shows the ignorance of the Liberian Government towards people with disabilities, and the desire to exclude a marginalized population.

Some people may argue that children with severe disabilities should be excluded from the classroom. Perhaps those people feel that children with severe cognitive disabilities are more a burden on the teacher, rather than an asset to the classroom. I would argue that children with severe cognitive disabilities add to the culture of diversity in a classroom. Although they may never be able to divide, multiply, or even communicate at the same level as their non-disabled peers, they create an environment that sensitizes children to differences. The presence of a diverse group of learners in a classroom teaches children compassion and patience. Andrew Solomon conducts research on the families of children with differences in the United States. He gave a TED talk in 2013 in which he told the story of a couple who had a child with Down syndrome. The

parents were upset at the educational opportunities offered in the United States for children with Down syndrome, so they opened a center in New York where children with Down syndrome could go to school. When asked if they wished their son, David, did not have Down syndrome, the parents stated,

Well, for David, our son, I regret it, because for David, it's a difficult way to be in the world, and I'd like to give David an easier life. But I think if we lost everyone with Down syndrome, it would be a catastrophic loss... For David, I would cure it in an instant to give him an easier life. But speaking for myself — well, I would never have believed 23 years ago when he was born that I could come to such a point — speaking for myself, it's made me so much better and so much kinder and so much more purposeful in my whole life, that speaking for myself, I wouldn't give it up for anything in the world. (Solomon, 2013, 11:15)

Parents, of course, want the best for their children. However, these parents' recognize the positive addition their son has made to their lives. People with severe cognitive disabilities have things to add to the lives of others. They may not be able to compete on a cognitive level with other peers their age, but one does not have to be of normal cognitive functioning to experience joy and bring happiness to others. This is something that many in the Liberian government fail to recognize. The exclusion of children with disabilities in the classroom because they may not be able to contribute to the intellectual discussion fails to take into account the socialization schooling teaches a child. Liberia is emerging from a dark period in its history. Teaching children that difference is acceptable is needed in a place where not just a few years ago difference in ethnicity could get one killed.

Teachers play a crucial role in the classroom. They are not only conveying knowledge and comprehension of educational standards, but also transferring societal norms. The teaching profession in Liberia is ripe with dysfunction from teachers not being paid to sexual bribery for grades to ghost teachers still on the payroll. These are important issues, which certainly demand time and energy to ensure that students are safe and teachers are compensated. However, for the Liberian Teacher Training Institutes (LTTI) currently enrolling new teachers or re-educating veteran teachers to new pedagogy, a module on difference in learning in the classroom would be advantageous to help teachers understand the learning needs of all students. LTTP, a program run by an American development agency, has a module on students with disabilities, but the employee interviewed stated that there was just not enough time to include the module (personal communication, November 28, 2012). These statements justify many in the government's ignorance and continue the cycle of marginalization for children with disabilities. There are successful examples in research (Johnstone & Chapman, 2009; Lewis, 2009) of countries conducting short workshops for teachers on including students with disabilities in the classroom where the teachers' attitudes towards these students positively changed. It is possible to include students with disabilities in a classroom in Liberia unless fear and stigma compels someone to do so.

The inclusion of people with disabilities in the early dialogue about construction could avoid the creation of a system of services that, as Pothier and Devlin (2006) pointed out "fail to respond adequately to the needs of people with disability" (p. 1). This has grave consequences which leave a, "a system of deep structural economic, social, political, legal, and cultural inequality in which persons with disabilities experience

unequal citizenship, a regime of dis-citizenship” (Pothier & Devlin, 2006, p. 1). The very idea that roads, sidewalks, public schools and government buildings that were destroyed in the war are not being rebuilt with access for people with disabilities might send an unconscious signal that people with disabilities are not worthy of access into these places. Perhaps, the government believes that it would be too expensive, but, as stated earlier, Metts (2007) suggested that for new buildings it is more cost-effective to apply those tenets of Universal Design in the beginning (p. 12). This discussion is about buildings that are being constructed right now without access. I understand that Liberia has many challenges and retrofitting buildings that are structural sound to create access for people with disabilities is not feasible now. The lack of ramps, accessible restrooms (or bathrooms in general) in newly constructed school buildings sends a signal to future generations that children with disabilities are not a part of society. If something does not change, children with disabilities may face the same difficulties current Liberian adults with disabilities face today.

This research examines the exclusion of people with disabilities in Liberia by looking at the influence of a Center for children with disabilities over the lives of the families associated with the Center. Children with disabilities are specifically targeted in the new education law. These issues need to be addressed, both legally and in the classroom. There are many challenges facing the Liberian education system, but getting students in the classroom is a priority. De-stigmatizing children with disabilities and letting them enter the classroom does not just offer acceptance into Liberian society, but the ramifications for educating all students has an impact on civil society.

### **Contributions, Limitations and Further Research**

This research set out to understand better the lives of a small group of families that have enrolled their children with differences in a Center that attempts to navigate the negative perceptions and social stigma of people with disabilities in Liberia. This case study is based on one Center with a focus on 10 families associated with it. This small sample size presents limitations because it is not completely representative of the entire population of people with disabilities in Liberia. I do hope that through the thick, rich description of the lives of these families, challenges people with disabilities may face are exposed. In addition, the families lived in an urban area. The difference between the urban and rural lives of people with disabilities was not included. Further research is needed with a larger sample size, which includes people with disabilities in both the rural and urban areas, as well as across disabilities. Longitudinal studies are needed to understand truly the lives of people with disabilities.

Further research is needed at all levels. There is little to no information on people with disabilities in Liberia and even less on children with disabilities. The census data appears to be unreliable and none of the NGOs have reliable data on the population of people with disabilities. There appears to be little attention paid to this population outside the NGO with a sole mission to help people with disabilities. Liberia is gaining ground in terms of development, but its policies are leaving people with disabilities marginalized and hidden in the shadows.

### **Concluding Thoughts**

I have provided an in-depth examination of some of the lives of people with disabilities in Liberia by examining the influence of the Center. This segment of the

population appears to have been largely neglected in the research on Liberia in post-conflict reconstruction. In addition, the lack of political will within the government seems to have made it nearly impossible for INGOs and NGOs to aid in the development of meaningful policy that might help people with disabilities. Students with disabilities are routinely denied education through the new education law and some are abused, abandoned, and neglected when placed in a boarding facility. Many different things need to be done before students with disabilities are invited in the classroom, before teachers are taught inclusive practices and before Liberian society is at a point to accept people with disabilities. The problem is that the list appears to be growing and people with disabilities are still at the very bottom, when recognized at all. The question is why are people with disabilities the last to be included? People with disabilities are human beings with rights. These rights are being violated by the neglect and ignorance of some officials in Liberian government.

Difference is not something to be feared. It is something to be rejoiced, for if each of us were the same, life would be boring and uneventful. People with disabilities are people with differences more extreme than the human brain can understand, which is why the English language sets those with disabilities apart to be those *with* something. The difference in those with disabilities should be considered an asset to the human experience, for they can teach us things like love, compassion, or patience, to name a few. People with disabilities are in every family. I will end with a quote from Andrew Solomon (2013). He stated, "...if you start to think that the experience of negotiating difference within your family is what people are addressing, then you discover that it's a

nearly universal phenomenon. Ironically, it turns out, that it's our differences, and our negotiation of difference, that unite us." (17:37)



**Appendix 1: Student Work**

**Appendix 2: The Center's Documents**

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