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Situation Analysis of Disability Resources and Needs of Shantytowns near Lima, Peru

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Running Head: ANALYSIS OF DISABILITY IN LIMA SHANTYTOWNS

Situation Analysis of Disability Resources and Needs of Shantytowns near Lima, Peru

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Abstract

Individuals in shantytowns of Lima, Peru experience unique challenges due to socioeconomic status and perceived inabilities. A situation analysis using qualitative ethnographic interviews of key participants (n=15) and one focus group (n=7) was conducted to explore life with disability in a shantytown of Lima, Peru. Findings showed that individuals with disability face physical and attitudinal barriers that limit social inclusion through the avenues of rehabilitation, education, and employment. The familial complex is expected to provide care for the individual with disability. The adult family member often chooses between providing income for the household and providing care and safety for their disabled family members. Females with disability without 24-hour supervision report experienced rape and sexual abuse. Participants and their caregivers expressed ideas to improve social inclusion of individuals with disabilities in their communities. Ideas expressed to improve quality of life for individuals with disability included improved access to education, rehabilitation and employment opportunities.

Situation Analysis of Disability Resources and Needs of Shantytowns near Lima, Peru

Disability is a broad-term for impairments, activity limitations, and participation restrictions that are associated with difficulty for an individual to fully participate with his/her environment. Disabilities can be mobility, sensory, cognitive or social in context. Individuals with disability experience more discrimination from social and political activities, lower levels of education, higher rates of poverty, and decreased levels of employment in comparison to non-disabled populations. Households with an individual with disability experience extra costs resulting from disability, and these households are more likely to experience food insecurity, poor housing, lack of access to safe water and sanitation, and inadequate access to health care.

Poverty is thought to be both a cause and consequence of disability. Over 80 percent of individuals with disability live in a developing country (Chandran, Hyder, & Peek-Asa, 2010).

Community-based rehabilitation (CBR) is an important strategy to meet the needs of people with disabilities, especially in developing countries (WHO, 2010a). CBR is implemented through efforts of individuals with disability, their families, organizations, communities, and relevant government and non-government organizations (NGOs). Goals of CBR include developing strategies for physical rehabilitation, equalizing opportunities, reducing poverty, and including individuals with disability in society (WHO, 2010a). Camino de Vida is a non-profit organization near Lima, Peru with interest in implementing a CBR program to meet these needs of the disabled population of Comas, Huaycan, and Villa el Salvador, Peru. Camino de Vida currently supplies charity wheelchairs through the non-profit organization Free Wheelchair Mission to disabled individuals in low-income areas of Peru. Camino de Vida is interested in implementing CBR to better meet the mobility needs and promote social, economic and political

inclusion for individuals with disabilities. Therapists and volunteers are willing to work in a CBR program, but they are seeking direction for initiating CBR.

Roughly 31% of Peru's 27.4 million people live with a disability (National Council for Integration of People with Disabilities, 2000). Only 12% of the disabled population has received rehabilitation services in Peru (Campoverde, Cervantes, & Ramirez, 2003). Less than 25% of adults with disability in Peru are gainfully employed, and 51.4% of disabled children do not attend school in Peru (Campoverde et al., 2003; Peru National Institute for Statistics and Information, 2007). According to the World Bank, 34.8% of Peruvians live in poverty, or on less than US \$2 each day, and over 14.7% live in extreme poverty, or less than US \$1.25 each day (World Bank, 2011). It is estimated that less than 1% of the buildings in Peru are handicap accessible, as defined by having ramp entries, widened doors and hallways for ease of wheelchair use, and elevators in buildings with multiple floors (National Council for Integration of People with Disabilities, 2000). Existing rehabilitation services in Peru are limited and costly resulting in poor access to rehabilitation for individuals living in poverty.

In June of 2011, the World Health Organization (WHO) published the World Report on Disability, the first comprehensive global disability analysis in over 30 years. This document identifies areas for further research, in particular qualitative research to better understand the lived experiences of individuals with disability, as the understanding of disability is limited in many less developed areas.

Statement of Purpose

The purpose of this study is to better understand the lives of those with disability, resources available, and resources needed in the shantytown communities of Comas, Huaycan, and Villa el Salvador near Lima, Peru.

Literature Review

Physical health, emotional barriers, environmental challenges, and social stigma are components of the complex idea of disability. According to the International Classification of Function, Disability and Health (ICF), disability is defined as a “dynamic interaction between health conditions and contextual factors” including both personal and environmental factors (WHO, 2011). According to the World Health Organization (WHO) social model of disability, an individual with disability’s participation in society is limited due to the combination of environmental and social barriers with an individual’s physical, psychological, or cognitive impairments (WHO, 2011). According to the WHO, currently there are over 650 million adults over the age of 18 living with disabilities in the world, and approximately 80 percent of those individuals live in a developing nation (WHO, 2011).

Although health conditions are not the sole factor in defining disability, health conditions related to infectious disease, chronic conditions, and injuries can all be a significant component to disability (WHO, 2011). Disability related to infectious diseases is more prevalent in low- and middle-income countries than high-income countries. Non-communicable chronic conditions, including cancer, heart disease and stroke, have a profound effect on disability rates in countries in all stages of development. Rapidly developing areas experience an upward trend in disability related to non-communicable diseases because of the increase in population age, lower fertility rates, reduction in infectious disease, and changing lifestyle habits including tobacco and alcohol use, diet and physical activity levels (WHO, 2011). Injuries from road-traffic accidents, violence and war, and occupational injury also contribute to disability rates, but the magnitude of contribution to disability is not well understood (WHO, 2011).

Disability can be both a cause and a consequence of poverty. Poverty can lead to disability through health conditions including low-birth weight, malnutrition, poor living conditions, unsafe work environments, and injuries (WHO, 2011). More than one-half of disabilities are preventable and can be directly linked to poverty (Parnes et al., 2009). For instance, disability can lead to poverty: empirical evidence indicates that families of a disabled individual experience both economic and social disadvantages at a higher rate than families without disabled individuals. Disability often results in lower levels of education, employment, financial earnings, and increased expenditures on health related issues (Parnes et al., 2009; WHO, 2011). The challenges related to disability tend to be greater in developing countries with inadequate health care systems, poor infrastructure, and limited budget for health care needs of their citizens (Maulik & Darmstadt, 2007; Parnes et al., 2009; Spiegel, Gosselin, Coughlin, Kushner, & Bickler, 2008). In developing areas, vulnerable groups, including women and individuals living in the poorest wealth quintile, have higher rates of disability (WHO, 2011).

Quantitative research related to disability in developing areas is limited; however a few socioeconomic trends are indicated. Children who are raised in poverty and have parents with low levels of education have higher rates of mental retardation (Aly, Taj, & Ibrahim, 2010). Children with disabilities have lower school attendance rates than non-disabled children (WHO, 2011). A study of 15 developing countries indicates that households with disabled members spend more on healthcare than households without disabled members (WHO, 2011). In Sierra Leone, households with a disabled member spent on average 1.3 times more on health care than non-disabled households. Households with disabled members have fewer assets and worse living conditions than households without disabled members (WHO, 2011). Data for household income varies; in Malawi and Namibia, households with a disabled member have significantly

lower incomes, but in Sierra Leone, Zambia and Zimbabwe, there is no significant difference in household income based on disability status (WHO, 2011). In an analysis of 13 developing countries, disability is associated with greater chance of poverty when poverty is measured as being in the lower two quintiles of wealth (WHO, 2011).

Community Based Rehabilitation (CBR)

Most disabled individuals, especially those in low- and middle-income countries or in rural areas have no access to institutional rehabilitation services. Having a disability in a developing area often labels the individual with a social stigma that leads to limited access to health care, education, and livelihood opportunities (WHO, 2010b). In the late 1970s, WHO developed the first generation of CBR with the attempt to extend rehabilitation and medical care to the disabled poor in developing areas. In 1994, the WHO, United Nations Organization for Education, Scientific and Cultural Development (UNESCO), and International Labor Organization (ILO) collaboratively developed the current concept of CBR that extends far beyond simply meeting medical and functional needs of the disabled population (WHO, 2010b). CBR is defined as “a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion for all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services” (WHO, 2002). In 2010, CBR had been implemented in at least 90 countries worldwide (WHO, 2010b). According to the WHO (2011), in areas with low levels of resources, CBR efforts should focus on identification of people with disability and referring them to appropriate resources and providing education to health workers and families in strategies to reduce secondary complications related to disability.

Although there is no standardization in studying the effectiveness of CBR, current literature indicates a promising outcome for CBR programs. In an analysis of 29 CBR programs in Asia, Africa and Latin America, Velema, Ebenso, and Fuzikawa (2008) reported that independence and social integration improved in at least 50 percent of CBR clients, roughly half of disabled children were enabled to attend school, and improved self-esteem in clients. Evidence indicates that quality of life of disabled individuals and caregivers of disabled individuals can improve with basic rehabilitation intervention (Velema, Ebenso, & Fuzikawa, 2008).

Context/Background

Peru is a rapidly developing country in South America with a population of 27.5 million people (Peru National Institute for Statistics and Information, 2007). Peru is geographically divided into “departments,” which are similar to “states” in the United States. Departments consist of “provinces” which are similar to “counties” in the United States, and provinces are made up of “districts,” which are similar to “townships” in the United States. Lima is the capital city of the country of Peru, and this capital city lies in the province and department called “Lima.” The Department, or State, of Lima is the most highly populated with approximately 8.5 million people (Peru National Institute for Statistics and Information, 2007). In 2010, the GNI per capita in Peru is US \$4,710 (World Bank, 2010). Peru has a high rate of disability: approximately 31% of Peruvians live with a disability, which is much higher than the global prevalence rate of disability of 15.6% (WHO, 2011). Only 12% of the disabled population has received rehabilitation services in Peru (Campoverde et al., 2003). Less than 25% of adults with disability in Peru are gainfully employed, and 51.4% of disabled children do not attend school in Peru (Campoverde et al., 2003). According to the World Bank, 34.8% of Peruvians live in

poverty, or live on less than US \$2 per day, and over 14.7% live in extreme poverty, or live on less than US \$1.25 per day. It is estimated that less than 1% of the buildings in Peru are handicap accessible (National Council for the Integration of People with Disabilities, 2000). Old buildings have not been updated to accommodate the mobility needs of individuals with disabilities; the doors are too narrow and there are no elevators or ramps in place of stairs. Even new buildings with ramps are often not accessible because the incline of the ramp is too steep (see Figure 1 and Figure 2). Rehabilitation services in Peru are limited and costly, resulting in poor access to rehabilitation for individuals living in poverty. According to the World Bank, in 2009, the average yearly health expenditure per capita in Peru was US \$201, and 75.7% of health care expenditures are out-of-pocket expenses.



Figure 1. Steep ramp into adolescent violence prevention center in Lima, Peru



Figure 2. Steep ramp at upper class outdoor mall in Lima, Peru

Most disability-related research is conducted in high-income areas, like the United States and Western Europe, however it is understood that the disability and poverty relationship differs greatly between developed and developing countries (WHO, 2011). In high-income countries, social systems assist disabled citizens through access to health care, provide payment for caregivers, implement special education programs within school systems, and develop non-discrimination laws and policies in the workplace and community life. Such social systems and laws are not present in many low- and middle-income countries. According to the World Health Survey (2004), the disability rate in high-income countries averaged 11.8% and 18.0% in lower income countries (WHO, 2011). In an analysis of data related to disability in 15 low- and middle-income countries, households with disabled members spend more on health care than those without disability. Quantitative data indicates that educational attainment and labor market opportunities are limited for individuals with disabilities in developing countries (WHO, 2011). In an analysis of 13 developing countries, disability is associated with a higher probability of being poor, when measured as by being in the lowest two quintiles of wealth (WHO, 2011). According to a 2005 survey investigating the United Nation's Standard Rules on the Equalization of Opportunities for Persons with Disability, 48 of 114 (42%) countries had not adopted policies related to rehabilitation, and 46 of 114 countries (40%) did not have an established rehabilitation program (WHO, 2011).

In Peru, the Department of Lima consists of 10 smaller provinces: Lima, Barranca, Cajatambo, Canta, Canete, Huaral, Huarochiri, Chancay, Oyon, and Yauyos. The province of Lima is divided into 43 smaller districts, or townships. The purpose of this study is to investigate community resources and needs for disabled individuals in the low-income districts of Comas, Ate, and Villa el Salvador in the province of Lima, Peru.

Camino de Vida is a non-profit social justice organization in Lima, Peru. The vision of Camino de Vida is to create life-changing partnerships with people around the world with those in need in Peru, South America¹. Current projects include an orphanage housing 30 children, some with special needs; a home for women with eating disorders; charity water projects in areas of Peru without a clean water source; cleft palate and cleft lip surgery for children; wheelchair distribution through FWM; microloans; and disaster relief (Camino de Vida, 2011). FWM is an international nonprofit organization committed to providing wheelchairs for disabled individuals living in poverty in developing nations². Free Wheelchair Mission wheelchairs are made of a plastic lawn chair, a metal frame, front wheel casters, and bicycle tires (see Figure 3). They are shipped to humanitarian organizations and faith-based organizations in developing countries to be assembled and given to the disabled poor. The design of the wheelchair is intended to reduce maintenance needs, and each wheelchair is distributed with tire patches and air pump to fix the most common problem of flat tires.

The efficacy of charity wheelchair distribution is conflicted in the current literature. Mukherjee and Samanta (2005) found that charity wheelchairs are unsuitable for outdoor independent mobility due to poor architectural design and geographic landscape. In contrast, Shore (2008) reported that 93.1 percent of charity wheelchair recipients reported using their wheelchair daily and an improved quality of life. Both articles indicate that proper assessment of the environment and abilities of the individual with disability must be completed to determine the efficacy of charity wheelchair use.

¹ For more information about Camino de Vida, see www.lifemissions.com

² For more information about Free Wheelchair Mission, www.freewheelchairmission.org



Figure 3. The Free Wheelchair Mission wheelchair

In Peru, the Department of Lima consists of 10 smaller provinces: Lima, Barranca, Cajatambo, Canta, Canete, Huaral, Huarochiri, Chancay, Oyon, and Yauyos. The province of Lima is divided into 43 smaller districts, or townships. Camino de Vida has distributed 49,000 FWM wheelchairs since 2003, and they continue to partner with FWM to provide wheelchairs for disabled individuals in need in Peru. Many of these wheelchair recipients are in the communities of Comas, Huaycan, and Villa el Salvador. Camino de Vida is interested in better understanding the resources available and needs of individuals with disability in these districts in order to better assist these individuals. The purpose of this study is to investigate community resources and needs for disabled individuals in the low-income districts of Comas, Ate, and Villa el Salvador in the province of Lima, Peru. This study will provide a qualitative evaluation to Camino de Vida regarding current resources and needs for disabled individuals in the communities of Comas, Huaycan, and Villa el Salvador from the perspective of community members.

Comas

The district of Comas lies north of the city of Lima. This community is one of the oldest shantytowns in the greater-Lima area. It has areas that are developed with retail stores and restaurants, but other areas have a poor infrastructure with dirt roads and no running water. Many houses are only accessible by rocky, steep walking paths (see Figure 4). The houses vary from middle class homes to shanty homes made of cardboard and tarps (see Figure 5). The population of Comas is 485,593 (Peru National Institute for Statistics and Information, 2007). According to the 2007 national census, 79,729 residents of Comas identify themselves as living with a disability.



Figure 4. Steep path to a participant's home in Comas, Peru



Figure 5. View of Comas, Peru

Huaycan

The district of Ate, which lies east of Lima, is a dry, rocky, mountainous area. In 2007 population of Ate was 476,231, and 66,316 residents of Ate identified themselves as living with a disability (Peru National Institute for Statistics and Information, 2007). Camino de Vida has concentrated work efforts in the shantytown of Huaycan, one of the most densely populated and poverty-stricken areas of Ate. Huaycan is built in the valley of several mountains, but the residential areas reach far up the hillsides (see Figure 6). Many homes are not accessible by automobile or motortaxi due to the rough, rocky terrain. Homes are often built of scrap wood or cardboard, and as the household obtains additional money, concrete bricks are added to the structure of the home. Homes are self-constructed by their owners, usually over many years. Many residents of Huaycan relocated there from the mountains in search of better opportunities for their families and education for their children. Makeshift or shantyhomes were built as a short-term solution to their housing needs, in hope of moving to the city of Lima once they saved enough money. However, work is difficult to find and wages are low for the unskilled laborer, so most households that move to Huaycan never have the opportunity to move to the city of

Lima. Over time, the simple houses that were intended to be their homes for a short period of time, become their permanent residences. Water is available from shared water pumps located outdoors between homes. Most homes do not have appropriate sanitation.

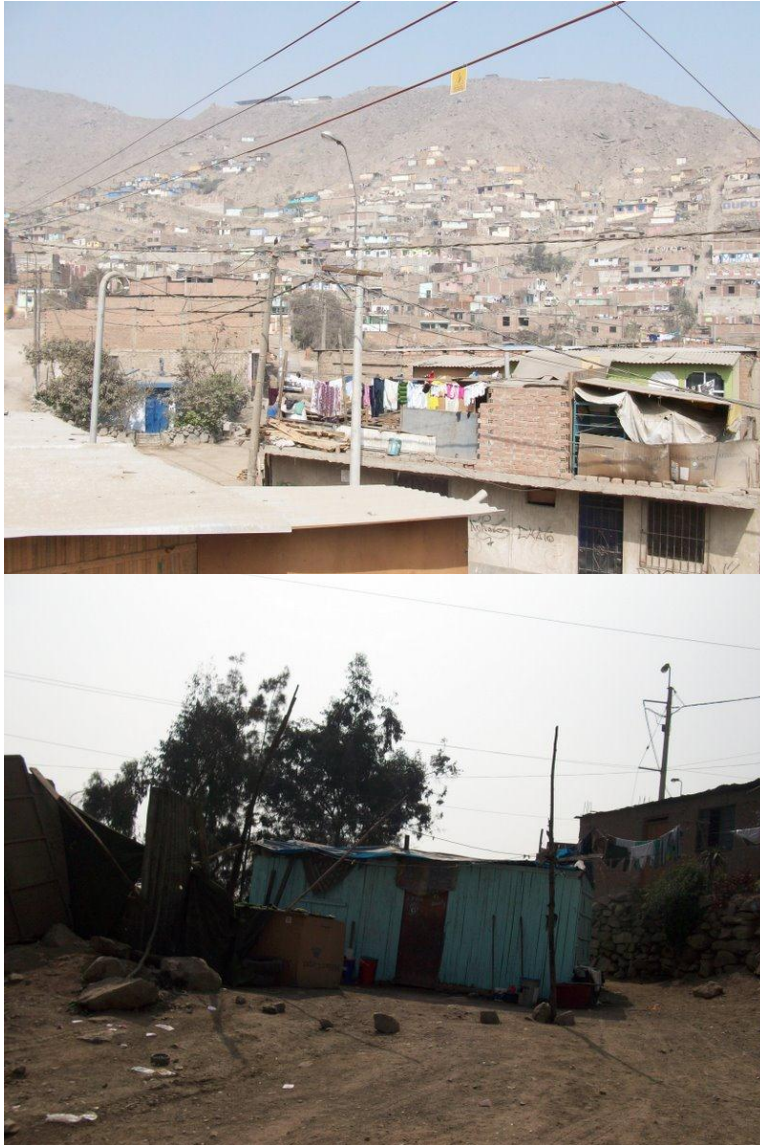


Figure 6. Huaycan and participant's house

Villa el Salvador

The district of Villa el Salvador lies south of Lima along the Pacific coast. It is one of the oldest shantytowns in Lima. Roughly thirty years ago, the local government set aside several city blocks for homes for individuals with disability. At that time, most of the disabled

population in Villa el Salvador had mobility deficits related to polio. Although those city blocks are no longer identified solely for housing of disabled individuals, Villa el Salvador has a history of being one of the few poor areas of Lima with resources for disabled individuals. The terrain of Villa el Salvador is less hilly than Huaycan or Comas, and the ground is sandy instead of rocky (see Figure 7). Most homes have dirt floors and do not have running water or sanitation in the home. In 2007 the population of Villa el Salvador was 381,082, and 47,747 residents identified themselves as living with a disability (Peru National Institute for Statistics and Information, 2007).



Figure 7. Villa el Salvador

Methods

The WHO recommends that the first step before the implementation of CBR is to conduct a situation analysis (WHO, 2010b). CBR programs must be based on information that is unique and specific to each community in order to meet the needs of that specific community.

According to the WHO framework for CBR, a situation analysis includes identifying what is known about people with disabilities and their living conditions through data collection of “the

environment, social, economic, cultural, and political situation at the national, regional and/or local level” (WHO, 2010b). Information gathering should also be conducted through in-depth personal interviews and review of current literature and government documentation.

A situation analysis of available and desired resources for individuals with disability in shantytowns of Lima, Peru was conducted through ethnographic methods, including participant observation, semi-structured interviews, and focus groups. In order to gather diverse information related to disability in these communities, 15 in-depth qualitative interviews with members of households with disability were conducted. The focus group and semi-structured qualitative interviews provided an opportunity to voice opinions openly in order to provide a deep understanding and rich description of living with a disability. Qualitative interviews elicited personal accounts of barriers and facilitators to individuals with disabilities in these communities. The focus group that was conducted consisted of five individuals with disabilities and two caregivers from the same community and the discussion focused on social integration and employment opportunities for disabled individuals in that community. Observation of individuals with disabilities, their environments and home life provided additional insights that did not occur through interviewing or informal conversations. Photography was utilized to capture the essence of life with disability in these communities. Ethical approval was received from Wright State University’s institutional review board (IRB) in Dayton, Ohio and additional approval was received from Camino de Vida in Lima, Peru.

The ethnographic qualitative study was conducted during August 2011. During this time I was familiarized with the socio-cultural and physical environment of the shantytowns of Comas, Huaycan, and Villa el Salvador near Lima, Peru. Visits were made to orphanages, therapy clinics, and a government funded pediatric rehabilitation hospital. Informal discussions

occurred with adults with disabilities, caregivers of adults and children with disabilities, community health workers, therapists, social workers, and humanitarian workers.

Households with a member with a disability were identified and recruited by Camino de Vida utilizing a database of recent recipients of charity wheelchairs. Purposeful sampling was used to identify participants representing a variety of disability types and ages representing a cross-section of the community. Subject inclusion criteria included residents of Comas, Huaycan, and Villa el Salvador, Peru age 18 years and older who were familiar with disability through personal experience, familial experience, or community-based knowledge. Community health workers, therapists, social workers, and humanitarian workers were also interviewed. They were identified by Camino de Vida through snowball sampling techniques. For instance, one therapist introduced me to a social worker who works with the disabled population within that community.

I was always accompanied by a community health worker or social worker who was familiar with the community health needs and participants in the study and a translator from Camino de Vida. The translator assisted in most communication, as my Spanish skills are basic. All participants were asked for oral informed consent prior to the interview or focus group. Additional consent was asked for taking photographs. Individuals with disability and their caregivers were interviewed in their homes. Length of qualitative interview varied from 20 to 75 minutes and consisted of open-ended questions of the following topics:

- 1) Perceptions of and attitudes concerning disability
- 2) Personal interaction with individuals with disability
- 3) Access and barriers to health resources for individuals with disability
- 4) Access and barriers to education resources for individuals with disability
- 5) Access and barriers to mobility aides for individuals with disability
- 6) Access and barriers to employment opportunities for individuals with disability

- 7) Openness to rehabilitation services for individuals with disability
- 8) The community's perception of resources needed to improve quality of life for individuals with disability
- 9) Any other topic that the interviewees wished to share related to life with a disability

The qualitative interviews ended when the interviewee had no additional information to add about life with disability. Following each interview and focus group, field notes were written-up, providing additional information for qualitative data analysis. The interviews and focus group were conducted in Spanish, with the assistance of an interpreter, and were digitally audiotaped and transcribed. The investigator used thematic coding to analyze the information from the qualitative interviews and focus group (Guest, MacQueen, & Namey, 2011). Thematic coding identified common themes related to disability found in literature review including the following: barriers to rehabilitation, barriers to employment, barriers to education, barriers to social integration, facilitators of health and social wellness, availability and use of durable medical equipment (DME), and self-perceptions and attitudes of others towards individuals with disability. Additional themes emerged inductively during data analysis. For instance, unexpected revealing situations were coded as "pearls." These unexpected themes included the notion that not all disability stories in shantytowns are sad and that disabled women report sexual abuse and rape. Names of individuals are fictitious in order to protect the privacy of the interviewees.

A summary of the qualitative data analysis from the semi-structured interviews and focus group were provided to Camino de Vida, and recommendations were given for future steps in pursuing a CBR program in the shantytowns of Lima, Peru.

Results

Characteristics of Participants

Fifteen homes with a disabled member were visited; there were 17 disabled individuals identified in those fifteen homes. Age ranges of the individuals with disability were 6 to 73 years. Eight of the individuals with disability were minors, under the age of 18. The most common diagnosis of disability was cerebral palsy (n=7). Key characteristics of the interviewees with disability are outlined in Table 1.

Five homes were visited in each of three shantytowns: Huaycan, Comas and Villa el Salvador. In Huaycan, five homes were visited, and three of the homes had one disabled family member, and two homes had two individuals with disability living there. Three of the seven disabled individuals were minors, so their adult caregivers were interviewed. In Comas, five homes were visited, and each home had only one family member with disability. One home that was visited in Comas had a minor with disability; in that case, the person interviewed was the disabled minor's father and aunt. In Villa el Salvador, five homes were visited, but only three interviews occurred. In one home, the disabled individual and caregiver were unavailable for interview. In another home, the disabled child was home alone, and the caregivers were unable to be located.

One focus group was conducted in the shantytown of Villa el Salvador consisting of five individuals with disabilities and two caregivers. Participants of this focus group were identified during a meeting of the disability advocacy group through the local government. The nature of this meeting was to discuss employment opportunities for individuals with disability. The local government was selecting disabled individuals to be recipients of retail carts to be used in the town square to sell food and other goods in order to increase the earning potential of disabled

individuals in the community. Information obtained from this group consisted primarily of topics related to employment and poverty-reduction of disabled households in this particular community.

Table 1. Characteristics of key participants

Age (yrs)	0-10 [1]	11-20 [7]	21-30 [1]	31-40 [1]	41-50 [2]	51-60 [0]	61+ [5]		
Marital status	Single [11]	Married [3]	Widowed [3]						
Disability type	Cerebral Palsy [7]	Polio [2]	Amputation [2]	Stroke [2]	Encephalitis [2]	Chronic conditions* [1]	Parkinson's disease [1]	Spina bifida [1]	
Age of disability onset (yrs)	Congenital [9]	0-10 [3]	11-20 [0]	21-30 [0]	31-40 [0]	41-50 [0]	51-60 [1]	61+ [4]	
Primary caregiver	Single parent [5]	Married parent [1]	Spouse [1]	Sibling under age 18 [2]	Child under age 18 [1]	Child over age 18 [3]	Grandmother [2]	Non-family member [1]	Does not need caregiver [1]
Provider of household income	Parent [8]	Disabled individual [1]	Sibling under age 18 [1]	Sibling over age 18 [1]	Child under age 18 [1]	Child over age 18 [3]	No income [2]		

[x], x = number of participants with characteristic

* Chronic conditions include heart disease and kidney disease

Poverty and Disability in Shantytowns of Lima

The connection between disability and poverty in shantytowns of Lima, Peru appears strong. A household with a disabled member will remain in poverty in most cases. Most of the homes visited in each community were one or two rooms, lacked clean water and sanitation, had dirt floors, and had gaps in the walls and roof providing little protection from the outdoor elements. Most homes had access to electricity, which was used to power one or two lights and a television and/or radio. In most cases, the electricity was “borrowed” from power lines by the home owners pulling electricity with a wire into their homes. The houses were cold, dark and damp inside and many of the disabled individuals I met were lying in bed covered with many blankets. Inside the homes were one or two beds, a couple chairs and a table. On the walls of a few homes were religious pictures and traditional artwork. Most families cooked over an open fire or propane stove.

Although the family structure of the fifteen households that visited varied greatly, family members were the caregivers for all, but one, of the houses visited. Without social programs or adequate income to pay for in-home care, family members must take up the burden of providing care for the person with disability. Single-parent households represented 77.8% of the households with a child with a disability. In two of the houses, the mothers had abandoned their family after their child was identified as having a disability. In these instances, the fathers provided income for the household, and an extended family member assisted with caring for the child with disability.

Gainful employment is difficult to find in a shantytown, so many fathers leave the home for weeks at a time in search of farming and mining work in the highlands east of Lima. Families do not have money to afford daily transportation to and from the areas in which the

fathers work. Although two families did have two parents, those households functioned as a single-parent household due to the absence of working fathers. The burden on the caregiver is great and caregivers as well as disabled individuals express feeling like prisoners in their own homes. In most cases, the caregiver stays home 24 hours each day, making it nearly impossible for her to provide additional income for the family. This is a double disadvantage since the expenses for households with a disabled member are greater than households without disabled members due to special needs for medical supplies, medicines, tests and health care visits. Caregivers report that diapers cost 2.50 soles each (equivalent of US \$0.90), often totaling 10 soles each day. When work is available, weekly income is reported at 100-150 soles (US \$37-55.50). After the expense of medications, often 5 soles per dose, and diapers, there is little money left over for food, clothing, home maintenance, and bills.

Since additional income is often needed in households with disabilities, caregivers are creative in trying to find ways to provide additional income. In two households, the primary caregiver of a child with disability earned income completing tasks that they could do in the presence of their disabled child. One mother washed clothes in buckets at home for neighbors earning a few soles each day. Another single mother collected recyclables from trash piles along the street while carrying her six-year-old son who had cerebral palsy. The income she earned selling the recyclables did not meet the needs for her four children; her income was supplemented by money from the father of one of her children.

Parents have to make the difficult decision between providing safety and supervision for their disabled children or additional income for their families. In two households, both the father and mother of a disabled child were absent from the home. In one household, siblings cared for the disabled child, and in the other household, the disabled child was left home alone. In the

case of Mariella, a 15 year old girl with cerebral palsy, her younger sisters, aged 6, 9, and 12 took turns staying home from school to care for their sister. The sisters reported that their father was at work in the mountains outside of town, and he likely would not return until next week. Their mother was away “travelling” and the girls were uncertain when she would return. For this family, the poverty cycle will continue as the children forfeit education in order to care for their sister while their parents are absent from the home.

In the case of a 14-year-old boy with cerebral palsy, the single mother had left the home to go to work in a store, leaving the disabled son home alone. He was inside the home with the door padlocked from the outside, providing the boy no way to escape the home. The neighbor reported that most days the mother leaves the boy sitting on a chair on his front porch, but today he was inside. When the neighbor went to the neighborhood store where she works, he was unable to find her there. What was this young boy to do if there was a fire? No one would be able to enter the home to help him. Understandably, his mother needed to provide income for the household, but that compromised the physical needs and a safe environment needed for a child to thrive.

In one single-parent household with two disabled children and four healthy children, the mother chose not to work in order to provide care for her children. One of her healthy sons works in construction and provides a modest income for their family. She reports that at times her family “must go without food so [they] can pay the bills.” She reports difficulty paying the water bill of 7.50 Nuevo soles/month (approximately US \$2.75/ month) and electric bill of 22 Nuevo soles/month (approximately US \$8.15/month). Her 11-year-old child with a disability has never seen a physician or been formally diagnosed, because there has been no money to visit the doctor. When asked about the family’s financial situation, the single mother says, “This is life,

my life. I am used to this now. Before I cried, but I do not cry anymore. This is my life.”

Disability affects not only the individual with the disability, but also their caregivers and the economic livelihood of the household.

Social Inclusion and Disability: Why are people with disabilities hidden in shantytowns?

As I walked through the streets and pathways of Comas, Huaycan, and Villa el Salvador, I could not help but wonder why I could not see any people with disabilities. Based on a review of literature, it can be expected that more than 15% of the population of poor areas has a disability, but in Comas and Huaycan I did not see a single person with disability outside of their home. They were all inside their homes, often lying in bed. One caregiver stated that his mother, who had advanced Parkinson’s disease, had not left her home in more than one year because it was too difficult to assist her up and down the steep path that led to their home.

A host of factors comprise the idea of social inclusion for individuals with disability, and the challenges of social inclusion are vastly different between low-income areas and high-income areas. Factors that affect social inclusion in developing areas include infrastructure, terrain, geography, safety and violence in the neighborhood, transportation, self-perception, and attitudinal barriers of others.

The roads to the interviewees’ homes often were not navigable by automobile or motortaxi³ (see Figure 8). The only way to reach most of the homes visited was on foot. Twice, in order to safely make it to the house, both hands and feet were used to climb the steep hillsides. Couple the steep hills, rocky terrain, winding pathways with weakness, balance difficulties, and poor safety awareness, and a person with disability easily becomes a prisoner within his or her

³ A motor taxi is a motorcycle with a carriage on the back that carries up to three passengers. This is a common mode of transportation in shantytowns as motortaxi rides are less expensive than car taxi rides and they are able to navigate steep hills and rocky roads better than cars. Typical motortaxi rides cost between 0.50 soles and 1.50 soles per passenger (approximately US\$0.18- \$0.55).

own home. In the case of 15-year-old Mariella, who has athetoid cerebral palsy, she remains confined in her home nearly every day. The 3 foot wide pathway around her home, to the main walkway lies along a 10-15 foot drop-off. Her sisters report that she can only leave her home when her father is available to carry her down the hillside. Her wheelchair is unable to navigate the steep, narrow, and rocky pathway. Her father works in the mountains for weeks at a time, and his visits home are infrequent. Without someone to help her down the hillside, Mariella is unable to attend school, church, community events, and socialize with non-family members. Despite the fact there is a school for children with special needs, Mariella has never attended school due to the fact her three sisters who act as her caregivers are unable to physically assist her to school.



Figure 8. Mototaxis in Huaycan, Peru

Although each household I visited had received a charity wheelchair within the previous two years, seven of the fifteen houses report that they never use the wheelchair because the wheelchair is unable to negotiate the terrain. Only one participant reported that he was able to use the chair independently, all other participants reported that they need assistance of a helper to navigate in the wheelchair outside the home. The style of wheelchair that each interviewee received does not fold, and therefore has limited portability. Even if the family could afford to

hire a taxi or motortaxi, the wheelchair does not fit in the taxi or motortaxi, thus limiting the mobility of the individual with disability once they have reached their destination.

Children and Disability: Why not school?

Although each community did have a school for children with special needs, seven of the eight children in this study do not attend school, and in each case the caregiver identified difficulty getting the child to school as the main barrier to education. Educational barriers expressed by the caregivers included: the school was too far away, the terrain was too difficult to navigate, and transportation by taxi or motortaxi was too expensive. Additional barriers to education reported by three caregivers were that the special education school was “a bureaucracy,” and that the admission and enrollment process were laborious and unfair. One community health worker reported that the special education school did not have appropriate equipment to meet the needs of special needs children. She stated, “The school does not have proper equipment. The children must sit in regular chairs and they tie them to the chair so they do not fall out of the chair.” The community health worker said she did not have trust in the special education school because of the lack of proper equipment and the teacher’s inadequate understanding of disabilities. If community leaders cannot recommend that caregivers pursue education for disabled youth, who will advocate for the education of the disabled child? Likely no one, and the child remains uneducated. Education leads to skill development, which leads to economic and income potential for the future. Children with disabilities who are isolated in their homes without access to education will remain in the throes of the poverty cycle.

Violence, Crime, and Disability

Shantytowns can be dangerous places, with densely populated areas and many people in desperate situations. On several occasions, community members advised caution as we travelled

about their communities: “Do not carry anything valuable” and “be aware of your surroundings” were common statements that I heard. Imagine being the caregiver of a child or adult with a disability in an area where robbery and violent crimes occur often. The individual with disability may have mobility deficits limiting their ability to physically move out of harm’s way in a reasonable amount of time. The individual with disability may have cognitive impairments that cloud one’s ability to make sound judgments in stressful situations. The individual with disability may have communication difficulties, limiting his or her ability to call for assistance if found in a dangerous situation. The individual with a disability could be an easy target for crime outside of the home. For this reason and factors discussed earlier, the individual with a disability often remains isolated at home.

But, is home a safe place for the individual with a disability? At least two interviewees were victims of rape in their own homes.

Elena’s Story

Elena is a vibrant 21-year-old female with cerebral palsy. She is friendly, curious, and social. Her speech is limited, but she can speak in simple complete sentences when given extra time. Elena lives with her mother, her 11-year-old brother who also has cerebral palsy, and four healthy siblings. Elena’s father does not live in the home. According to her mother, the father is an alcoholic and she does not allow him to visit. She states, “When he comes around, I throw things at him to keep him out of my house.” Their home is three small rooms, one of which does not have a roof. The floors are made of dirt. There is no sanitation system or running water.

According to a community health worker, Elena was raped at the age of 16. Elena was discovered to be expecting a child when she was seven months pregnant.

Once she was identified as pregnant, she was sent to live in a government institution for disabled youth. Elena's son lives in an orphanage for children of disabled and/or mentally ill women. Most of these children were conceived through an act of rape. The rape occurred when her single mother was out of the home working to provide an income for the family. Once the mother could prove that she was able to provide 24 hour care, her daughter returned home.

Rebecca's Story

Rebecca is a 34-year-old female with severe spastic cerebral palsy who lives with her mother. Rebecca cannot walk, sit up, or roll over on her own. She has spent most of her life lying in bed. Until she started going to therapy in the past year, she had been unable to speak and unable to feed herself. Rebecca's mother works outside the home, and Rebecca is left home alone all day. She has two children under the age of 10, who are both the result of rape. Rebecca's mother cares for her and her children.

In both of these stories, young women with disabilities were raped within their own homes when they were without the supervision of a caregiver. Their mothers made the difficult choice of seeking income over providing 24-hour care for their disabled children. Men in the community saw these women as objects, rather than individuals to be respected. Women with disabilities are an easy target for sexual violence because they are without a voice to be heard. Their silence can be physical, manifested in the inability to speak, but it also is figurative, as the disabled individual is not respected in the community. The community may choose not to listen when they speak. It can be assumed that their stories are similar to those of other women with disabilities in these communities. Therapists and community health workers report that rape is

common, especially among female with disabilities. Unfortunately, individuals with disabilities can be victims of violence both inside and outside their own homes.

Family and Disability

Caregivers' Perception of Disabled Children

When a family is living in a mentality of just surviving until the next day, the disabled family member is often overlooked and undervalued. Little time is spent investing in the disabled individual and working towards developing their motor, communication and cognitive skills. In several homes, individuals with communication difficulties, especially family members with cerebral palsy, were not viewed by their caregivers as having the ability to think. Caregivers typically have little education, often only three or four years of formal schooling. Health care providers have not educated the caregivers in techniques to maximize the potential of the disabled individual. Many caregivers knew little, if anything, about the diagnosis of the disabled individual. My physical therapist eyes saw the potential in the individuals with disabilities; despite their difficulty communicating vocally, it was evident that many understood and desired to socially interact with others. Their eyes were bright and made contact with us, and smiles formed when they were spoken to, hugged, and touched. My clinical impression is that if given the opportunity to develop their communication skills, many of the non-verbal disabled individuals would be able to communicate with others either through spoken word or assistive technology⁴. The lack of opportunity for individuals with disability often begins in the home.

⁴ Assistive technology includes communication boards and adapted computer software utilized by individuals with disability to increase the possibility to better participate in society and live independently (Eide & Oderud, 2009). The UN Convention on the Rights of Persons with Disabilities (UN, 2006) calls for states to provide disabled individuals with mobility aids, devices, and assistive technology in order for disabled individuals to have equal opportunities and improved independence. However, in low-income countries, it is estimated that only 1-2% of individuals with disability receive such services (Eide & Oderud, 2009).

Rebecca's Story

For 34 years, Rebecca had little opportunity to interact with other people. Living with severe cerebral palsy, she spent nearly every day bed-ridden, surrounded by newspapers to sop up her waste as her mother went to work. She was unable to speak and did not attempt to communicate or interact with her surroundings. She was unable to feed herself. Several months ago, a rehabilitation organization learned of Rebecca's story and situation, and she began attending a rehabilitation clinic one time each week. Her mother told the rehabilitation specialists that her daughter did not have potential to improve, but she was willing to allow the rehabilitation specialists to pick up Rebecca and bring her to their clinic weekly. By the end of the first session, Rebecca verbalized one single word to the rehabilitation specialists: "pee-pee." The rehabilitation specialists helped her sit on the toilet, and she used the restroom. The rehabilitation specialists saw potential in her, and continued to bring her to the clinic weekly. When I visited the rehabilitation clinic, only four months later, Rebecca was able to speak in complete sentences: "I want music" and "I don't like that." After four months, she was able to feed herself. It is evident that she has the ability to learn and be more independent; however, this potential was not seen by her caregiver.

What happened at the rehabilitation clinic that encouraged Rebecca to speak and be heard for the first time? Someone was willing to give her the opportunity to speak and the extra time required to do so. What would Rebecca be like today if her potential was realized when she was young? What if she had received rehabilitation services starting at a young age? How many children with disabilities are not given the opportunity to develop their skills?

Family support and disability

The family unit in Peru is strong, and the family is the default caregiver for individuals with disability in low-income Peruvian families. Hired caregivers cost 1500 Nuevo soles/month (approximately US \$555/month), making it a luxury accessible only to the wealthy. Louisa is an elderly woman with chronic health issues who is bed-ridden. Her husband of over 50 years quit his job in order to care for his wife when her health began to deteriorate 10 years ago. Working as a baker, his monthly income was 500 Neuvo soles (approximately US \$185/month) and they were able to live a decent life off his salary until his wife became disabled. He said, “I would like to hire help so that I can work as a baker, but it is not possible to pay their wages [1500 Nuevo soles/month]. I miss baking.” Fortunately, Louisa has family who is able to provide care for her, and her adult children provide income for the family. Not all disabled individuals in shantytowns are as fortunate.

Pedro's Story

Pedro is a 73-year-old man who was working as a distributor of potatoes to local markets until last year. His job required him to carry sacks of potatoes, weighing at 50 pounds or more. According to community members, he was one of the strongest and most respected men in the community. However, one day while he was at work, he developed weakness of the left side of his body and fell. Since that day, he has been unable to work, and for several months following the incident he was unable to walk. His mobility has improved, and now he is able to walk with the assistance of a walker.

The stroke that Pedro suffered did not only cause him to lose his job and his income, soon after suffering the stroke he lost his house. Without the ability to work, he was unable to provide income he needed to pay for his wife's funeral and pay the lease to

of his house. Without any children or living family, Pedro quickly found himself homeless. He now resides in the back room of a soup kitchen in a shantytown.

Volunteers from a local church have provided him with clothes, meals, and provide physical assistance for bathing and dressing him. According to the community health worker, Pedro has applied to live in a government institution for the elderly without family. However, because he has health issues and requires a caregiver to assist with showering, dressing and meal preparation, he was denied residence there. She stated that elderly homes are only for healthy elderly people in Peru. Instead, Pedro stays in the small, dark, dusty room behind the community soup kitchen, wishing people would visit him. He is tearful and lonely.

How many other disabled individuals are without family, and caregivers, in Peru? How many others with disability have been forced into homelessness? The family unit can be an asset, when they have the ability to provide adequate care for disabled family members. But, when the family unit is broken or a disabled individual has no family, an individual with disability will be without adequate care and support. In the shantytown, support is given by families, almost exclusively. Neighbors and social programs provide little, if any, assistance to families with members with disabilities.

Rehabilitation, Disability, and Poverty: Why Not Rehabilitation?

Rehabilitation is a means by which mobility, self-care, communication, and recreation are maximized. Of the fifteen shantytown homes I visited, only one household's disabled members were currently receiving rehabilitation services. In this household, there were two individuals with disability, and the rehabilitation services they received were free of charge and transportation was provided. In the other homes, lack of money and lack of transportation were

identified as the main barriers to rehabilitation. Two other interviewees, one man with a history of stroke and one man with a history of an above-knee amputation, did not know that rehabilitation services would benefit their condition. They reported that physicians never recommended rehabilitation to them. Eight of the 15 interviewees had received rehabilitation services previously in clinics, and all of those clinics were several miles from the home of the individual with disability. All of them cited lack of money for transportation as the reason that they discontinued rehabilitation services.

No rehabilitation in individuals with disabilities leads to decreased levels of independence with mobility, self-care and communication, thus contributing to the social exclusion of individuals with disabilities in shantytowns. Social inclusion affects quality of life of the individual with disability; education, friendships, recreation, and employment opportunities are key areas of life that are limited by social exclusion.

Martin's Story

Martin worked in construction as a concrete and plaster expert. He was well-known in the community as one of the best in construction. He made a good living, supported his large family, and was happy. One day, while at work he stepped on a nail, but due to diabetic neuropathy, he did not feel the sharp object in the foot. By the time Martin realized that the nail was in his foot, it had become infected. The infection was severe and antibiotics and wound care did not improve the infection. Eventually, his leg needed to be amputated above-the-knee in order to get rid of the infection.

When I met Martin in his home, he was sitting at the kitchen table and he was sad. He said he was sad because he could no longer work at his job, which he loved very much. He said it is impossible to heavy labor jobs from a wheelchair or while using

crutches. When I asked about prosthesis, he reported that they could not afford prosthesis. Without a prosthesis, he would not be able to walk. Without being able to walk, he would not be able to work. He said his family was now poor because he could not work.

For Martin, the barrier to rehabilitation and prosthesis was money. Without money to pay for these services, his independence would not significantly improve. In the shantytowns of Lima, Peru, rehabilitation services are not utilized because there is no money available for such services, despite the fact that 100 percent of the interviewees reported that rehabilitation would improve their conditions.

Discussion

Where do we go from here?

Although the United Nations' Millennium Development Goals do not specifically address disability, one of the goals is to reduce poverty by one half by 2015. Social inclusion of individuals with disability is an integral component of achieving this goal. The former president of World Bank, John Wolfensohn, stated, "If development is about bringing excluded people into society... then unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half" (Mji, Maclachlan, Melling-Williams, & Gcaza, 2009). This present study is an initial attempt to identify the available resources and needs of individuals with disabilities in the shantytowns near Lima, Peru. I was able to identify barriers to resources and current facilitators of social integration in these communities which led me to the following recommendations for organizations, like Camino de Vida, who are considering community based rehabilitation.

Educate families about the potential of children with disabilities

The lack of opportunity for the child with disability often begins within the home. Parents, grandparents, siblings, and other caregivers do not see the potential of the child with a disability. Caregivers do not see the benefit of sending their child with a disability to school. Community based rehabilitation programs can play a key role in providing education to caregivers to maximize the potential of the disabled child. Education topics can include the following: (1) maximizing communication, mobility and self-care of the disabled child; (2) education for the child with disability, (3) nutrition and the individual with disability, and (4) psychological, physical and sexual health of the individual with disability. Support groups for individuals with disabilities and their caregivers could develop partnerships between community members and advocacy groups for the inclusion of disabled individuals into the community. As potential is recognized in individuals with disability, respect and social inclusion will improve.

Location matters in community based rehabilitation

Key components to social inclusion for the disabled individual within their community are access to education, rehabilitation and employment. For residents of shantytowns near Lima, Peru, the main barriers to education and rehabilitation are lack of money and lack of transportation. Schools and rehabilitation clinics are typically too far away to walk to, and the household has no money to hire taxi or motortaxi transportation. Thus, it is important to advocate for transportation of disabled children to the public schools. Community based rehabilitation programs should be located in accessible areas by individuals with disabilities. It may not be feasible to utilize one building to serve as a rehabilitation clinic for the entire shantytown. A mobile community based rehabilitation program may be better utilized by individuals with disability and their caregivers. One may consider renting a room in a

community building, like a place of worship or soup kitchen, one day per week, so that individuals with disabilities within a few blocks can more easily access the rehabilitation program. Another day or the week, the clinic could be set up in a different part of the community. Each location can target interventions to meet the specific needs of the individuals with disability that attend the rehabilitation program.

Volunteers are assets to community based rehabilitation

Non-disabled community members whom I met expressed an interest in assisting and working with disabled individuals in their community, but they were unsure of how to do so. Community based rehabilitation can utilize volunteers to supplement rehabilitation and health professionals in their program. Educating volunteers on identifying the needs and assets of the disabled person and based rehabilitation techniques, like range of motion exercises and self-care techniques, will promote partnerships between the community and the disabled community members. Identification of volunteers can occur at religious organizations, local colleges, and other community organizations. Physical therapy, occupational therapy and speech therapy education is available at universities in Lima, Peru. Community based rehabilitation programs should consider partnering with local universities to provide service learning experiences for therapy students. These students would benefit from the hands-on experience while the community based rehabilitation program would benefit from increased manpower for minimal to no cost.

Employment for the individual with disability

Adults who acquire a disability report difficulty returning to work in the shantytowns. Most employment opportunities in shantytowns are manual labor jobs, and a new disability that affects mobility makes it nearly impossible to return to work. Vocational rehabilitation is a strategy

within community based rehabilitation that assists and trains individuals with disability to find meaningful work to provide income for their households. Not all individuals with disabilities are candidates for vocational rehabilitation. It will be important to partner with businesses in the community and advocate for the employment opportunities for individuals with disability. By encouraging business owners to hire individuals with disability, it would allow individuals with disability to be seen for their abilities, rather than their challenges. In turn, respect and social inclusion of the individual with disability would improve.

Happiness with life with disability in a shantytown

Although most interviewees with disabilities expressed feelings of helplessness, frustration, and worry, I was surprised when two interviewees expressed that they were content with life. One interviewee who has been unable to walk since contracting polio that affected both of his legs at the age of one said, “My life is good. I cannot complain.” The two individuals who said they were happy had these factors in common: (1) positive family support and (2) social integration within their community. Both expressed that they ventured outside the home on a nearly daily basis, had many friends, and had plans for their futures. Despite the economic challenges and physical barriers in the community, it is possible to be happy and have a healthy outlook on living with a disability in a shantytown.

Limitations

This study speaks only from the perspective of individuals with mobility-related disabilities and their caregivers. The needs of those with only cognitive, mental health, or sensory related disabilities may differ greatly than those with mobility challenges.

Future Considerations for Research

This study is only an initial attempt to understand the barriers to rehabilitation and social integration of individuals with disability in shantytowns of Lima, Peru. Additional questions arose during the interview and analysis process. Specifically, the issue of sexual health, sexual and domestic violence, and rape of disabled females were themes expressed in the stories of two disabled and multiple community health workers. The issues that surround sexual health in disabled individuals related to access to sexual health care and treatment should be further investigated. Employment opportunities for the individual with disability appeared limited in shantytowns. Additional research looking at types of income-generating jobs for individuals with disability is needed. Questions arose regarding the capacity of special education schools and the process of enrollment of children with disabilities to these schools. Additional research investigating the fitness of special education programs in the shantytowns of Lima, Peru is also needed. Additional research is needed to better understand the differences of life with disability for males as compared to females in the shantytowns.

Conclusion

This study indicates that physical limitations are not the sole reason for social exclusion of disabled individuals in shantytowns of Lima, Peru. The perceptions of others, especially caregivers, limit the potential of individuals with disability. Environmental barriers, including steep and rocky terrain and inaccessible community buildings are indicated as barriers to education and rehabilitation for individuals with disability. It is expected that as accessibility of buildings, education, rehabilitation, and employment opportunities improve, advancements in health, quality of life, social inclusion and the livelihood of these communities will be noted.

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Appendix 1 – Public Health Competencies Met

Specific Competencies
Domain #1: Analytic Assessment Skill
Defines a problems
Determines appropriate uses and limitations of both quantitative and qualitative data
Selects and defines variables relevant to defined public health problems
Identifies relevant and appropriate data and information sources
Evaluates the integrity and comparability of data and identifies gaps in data sources
Applies ethical principles to the collection, maintenance, use, and dissemination of data and information
Partners with communities to attach meaning to collected quantitative and qualitative data
Makes relevant inferences from quantitative and qualitative data
Obtains and interprets information regarding risks and benefits to the community
Applies data collection processes, information technology applications, and computer systems storage/retrieval strategies
Recognizes how the data illuminates ethical, political, scientific, economic, and overall public health issues
Domain #2: Policy Development/Program Planning Skills
Collects, summarizes, and interprets information relevant to an issue
Develops a plan to implement policy, including goals, outcome and process objectives, and implementation steps
Domain #3: Communication Skills
Communicates effectively both in writing and orally, or in other ways
Solicits input from individuals and organizations
Advocates for public health programs and resources
Uses the media, advanced technologies, and community networks to communicate information
Effectively presents accurate demographic, statistical, programmatic, and scientific information for professional and lay audiences
Attitudes
Listens to others in an unbiased manner, respects points of view of others, and promotes the expression of diverse opinions and perspectives
Domain #4: Cultural Competency Skills
Utilizes appropriate methods for interacting sensitively, effectively, and professionally with persons from diverse cultural, socioeconomic, educational, racial, ethnic and professional backgrounds, and persons of all ages and lifestyle preferences
Identifies the role of cultural, social, and behavioral factors in determining the delivery of public health services
Develops and adapts approaches to problems that take into account cultural differences
Attitudes
Understands the dynamic forces contributing to cultural diversity
Understands the importance of a diverse public health workforce

Domain #5: Community Dimensions of Practice Skills
Establishes and maintains linkages with key stakeholders
Utilizes leadership, team building, negotiation, and conflict resolution skills to build community partnerships
Collaborates with community partners to promote the health of the population
Identifies how public and private organizations operate within a community
Identifies community assets and available resources
Develops, implements, and evaluates a community public health assessment
Domain #6: Basic Public Health Sciences Skills
Defines, assesses, and understands the health status of populations, determinants of health and illness, factors contributing to health promotion and disease prevention, and factors influencing the use of health services
Identifies and applies basic research methods used in public health
Applies the basic public health sciences including behavioral and social sciences, biostatistics, epidemiology, environmental public health, and prevention of chronic and infectious diseases and injuries
Identifies and retrieves current relevant scientific evidence
Identifies the limitations of research and the importance of observations and interrelationships
Attitudes
Develops a lifelong commitment to rigorous critical thinking
Domain #8: Leadership and Systems Thinking Skills
Creates a culture of ethical standards within organizations and communities
Helps create key values and shared vision and uses these principles to guide action
Identifies internal and external issues that may impact delivery of essential public health services (i.e. strategic planning)
Facilitates collaboration with internal and external groups to ensure participation of key stakeholders
Promotes team and organizational learning

Appendix 2 - IRB Approval Letter

Office of Research and Sponsored Programs
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Dayton, OH 45435-0001
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DATE: July 28, 2011
TO: Jessica Hunt, PI, Graduate Student
Community Health
Cristina Redko, Ph.D., Faculty Advisor
FROM: B. Laurel Elder, Ph.D., Chair 
WSU Institutional Review Board
SUBJECT: SC# 4544
'Situation Analysis of Disability Resources and Needs: Comas, Huaycan, and Villa el Salvador Shantytowns Near Lima, Peru'

This memo is to verify the receipt and acceptance of your response to the conditions placed on the above referenced human subjects protocol/amendment.

These conditions were lifted on: 07/28/2011

This study/amendment now has full approval and you are free to begin the research project. If this is a VA proposal, you must still receive a letter of approval from the Research and Development Committee prior to beginning the research project. This implies the following:

1. That this approval is for one year from the approval date shown on the Action Form and if it extends beyond this period a request for an extension is required. (Also see expiration date on the Action Form)
2. That a progress report must be submitted before an extension of the approved one-year period can be granted.
3. That any change in the protocol must be approved by the IRB; otherwise approval is terminated.

If you have any questions concerning the condition(s), please contact Jodi Blacklidge at 775-3974.

Thank you!
Enclosure

RESEARCH INVOLVING HUMAN SUBJECTS

SC# 4544

ACTION OF THE WRIGHT STATE
UNIVERSITY
EXPEDITED REVIEW
Assurance Number: FWA00002427

Title: *'Situation Analysis of Disability Resources and Needs: Comas, Huaycan, and Villa el Salvador Shantytowns Near Lima, Peru'*

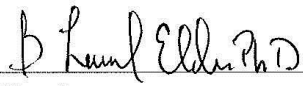
Principal Investigator: Jessica Hunt, PI, Graduate Student
Cristina Redko, Ph.D., Faculty Advisor

Department: Community Health

Expedited Category: 6, 7

The Institutional Review Board has approved the use of human subjects on this proposed project with conditions previously noted. The conditions have now been removed.

REMINDER: FDA regulations require prompt reporting to the IRB of any changes in research activity, changes in approved research during the approval period may not be initiated without IRB review (submission of an amendment), and prompt reporting of any unanticipated problems (adverse events).



Signed Chair, WSU-IRB

Expedited Review Date: July 15, 2011

IRB Meeting Date: August 15, 2011

This approval is effective only through: July 14, 2012
To continue the activities approved under this protocol you should receive the appropriate form(s) from Research and Sponsored Programs (RSP) two to three months prior to the required due date. If you do not receive this notification, please contact RSP at 775-2425.

Informed Consent

I am being invited to participate in this research study because I live in Comas, Huaycan, or Villa de Salvador, Lima, Peru. This research study is being performed to assess the community resources available for individuals with disability in these communities. This information will be given to Camino de Vida organization in Lima, Peru.

1. I understand that participation in the interview will take up to 60 minutes of my time.
2. I know that the final material will not include my name or any other identifying information.
3. I know that participating in this interview is entirely my choice.
4. I know that there are no known personal risks or benefits from participation in this study.
5. I know that I can stop participating in this interview at any time any for any reason without negative consequences.
6. I know that no payment or reward of any kind will be given to me for participating in this study.
7. I know that by participating in this interview I am giving my permission for the information that I provide to be used by the primary investigator and Camino de Vida.
8. I know that the interviewer may ask to take my photograph. I can refuse to be photographed and still participate in the interview. I know that photographs will only be used for educational purposes.

I consent to participating in the interview.	Yes	No
I consent to being photographed.	Yes	No

Signature

Date

WSU-IRB
APPROVED 7/28/11
GOOD THRU 7/14/12

Informed Consent Translated to Spanish**Consentimiento Informado**

Yo estoy siendo invitado para participar en este estudio de investigación porque yo vivo en Comas, Huaycan, o Villa el Salvador, Lima, Perú. Este estudio de investigación está siendo dado para evaluar los recursos de la comunidad que están disponibles para los individuos con discapacidad en estas comunidades. Esta información será dada a la organización en Camino de Vida en Lima, Perú.

1. Yo entiendo que la participación en la entrevista tomara hasta 60 minutos de mi tiempo.
2. Yo se que el material final no incluye mi nombre o ningún otra información de identificación.
3. Yo se que participando en esta entrevista es completamente mi decisión.
4. Yo sé que no hay riesgos personales conocidos o beneficios en participar de este estudio.
5. Yo sé que puedo dejar de participar en esta entrevista en cualquier momento por cualquier razón sin consecuencias negativas.
6. Yo se que ningún pago o premio se me está dando por participar en este estudio.
7. Yo se que participando en esta entrevista yo estoy dando mi permiso para la información que yo provea para ser usado por el investigador principal y Camino de Vida.
8. Yo entiendo que el entrevistador puede que me pregunte para tomarme una foto. Yo puedo negarme de la foto, pero igual participar de la entrevista. Yo se que las fotos solo serán usadas para propósitos educacionales.

Doy mi consentimiento para participar en esta entrevista. Si No

Doy mi consentimiento para ser fotografiado. Si No

Firma

Fecha

WSU-IRB
APPROVED 7/28/11
GOOD THRU 7/14/12

Informed Consent Back-Translated to English

Consentment Information

I am being invited to participate in a study because I live in Comas, Huaycan, or Villa el Salvador, Lima, Peru. This study is being given to evaluate the community resources that are available for those disabled individuals in these communities. This information will be given to the organization Camino de Vida, in Lima, Peru.

1. I understand that the participation in the interview will take up to 60 minutes of my time.
2. I realize that the final matierial will not include my name or any other information that would identify me.
3. I realize that participating in this survey is completely my decision.
4. I realize that there is no known personal risks or benefits by participating in this survey.
5. I realize that I can refuse to participate in this survey at any moment for any reason without any negative consequences.
6. I realize that there will not be any prize or compensation if I participate in this survey.
7. I realize that by participating in this survey I am giving permission to the primary surveyor and Camino de Vida to use my information.
8. I realize that the surveyor can ask to take my picture. I can deny having my picture taken but can still participate in the interview. I realize that the pictures will only be used for academic purposes.

I give my consent to participate in this survey	Yes	No
I give my consent to be photographed.	Yes	No

Signature

Date

WSU-IRB
APPROVED 7/28/11
GOOD THRU 7/14/12

Appendix 3 - Interview Tool

Interview Questions

Background Information of Interviewee:

- 1) What is your age?
- 2) Are you married?
- 3) How many children do you have?
- 4) Who provides income for your family?
- 5) What is your/their job?
- 6) How long have you lived in this community?

Disability questions:

- 7) Do you or anyone you know have a disability?
 - a. Difficulty seeing?
 - b. Difficulty communicating?
 - c. Difficulty hearing?
 - d. Difficulty walking?
 - e. Emotional problems?
 - f. Have an amputation?
 - g. Any conditions that limits ability to participate in community activities?
 - h. Any conditions that make it difficult to care for themselves like dressing, bathing, and feeding?
- 8) If you answered “yes” to knowing someone with a disability, can you tell me more about them?
- 9) If a person with disability in your community needed health or rehabilitation services, where would they go? How much would the services cost?
- 10) What is your opinion of children with disability going to school in your community?
- 11) What do you think about job opportunities for adults with disabilities in your community?
- 12) Tell me what you know about equipment to help people with disabilities.
- 13) Where would a person with disability in your community obtain equipment to help them?
- 14) What resources would you like to be made available for individuals with disability in your community?
- 15) What should I have asked you about disability in your community that I did not think to ask?

Interview Questions Translated to Spanish

Preguntas del Cuestionario

Historial del entrevistado:

- 1) ¿Qué edad tienes?
- 2) ¿Estás casado?
- 3) ¿Cuántos hijos tienes?
- 4) ¿Quién provee para tu familia?
- 5) ¿Cuál es tu salario (o el que provee para la familia)?
- 6) ¿Cuánto tiempo has vivido en esta comunidad?

Sobre su discapacidad:

- 7) Tienes tu o alguien que tu conozcas una discapacidad?
 - a. ¿Dificultad viendo?
 - b. ¿Dificultad comunicándose?
 - c. ¿Dificultad escuchando?
 - d. ¿Dificultad caminando?
 - e. ¿Problemas emocionales?
 - f. ¿Tienen/tienes una amputación?
 - g. ¿Alguna condición que limite la participación en actividades de la comunidad?
 - h. ¿Alguna condición que hace difícil el cuidarse de sí mismos como vestirse, bañarse o alimentarse?
- 8) Si respondiste “sí” porque conoces a alguien con discapacidad, ¿puedes decirme más acerca de ellos?
- 9) Si la persona con discapacidad en tu comunidad necesitara servicios de salud o de rehabilitación, ¿A dónde irían? ¿Cuánto les costaría los servicios?
- 10) ¿Cuál es tu opinión sobre los niños con discapacidad que vayan al colegio en tu comunidad?
- 11) ¿Qué piensas sobre las oportunidades de trabajo para adultos con discapacidad en tu comunidad?
- 12) Dime que sabes acerca de equipos para ayudar a los discapacitados.
- 13) ¿Donde obtendría una persona con discapacidad su equipo para ayudarse?
- 14) ¿Cuáles son los recursos que te gustaría que estén al alcance para los individuos con discapacidad en tu comunidad?
- 15) ¿Qué te he debido preguntar sobre discapacidad en tu comunidad que no te pregunte antes?

Interview Questions Back-Translated to English

Interview Questions

Background:

- 1) How old are you?
- 2) Are you married?
- 3) How many children do you have?
- 4) Who is the financial provider of the family?
- 5) What is your salary (or of the person who is the primary provider)?
- 6) How long have you lived in this community?

Regarding their disability

- 7) Do you or anyone that you know have a disability?
 - a. Difficulty seeing?
 - b. Difficulty communicating?
 - c. Difficulty hearing?
 - d. Difficulty walking?
 - e. Emotional problems?
 - f. Do you have an amputation?
 - g. Do you have a condition that limits your participation in community activities?
 - h. Any condition that makes it difficult to take care of yourself like dressing, washing or feeding yourself?
- 8) If you responded "yes" because you know someone who has a disability can you tell me more about them?
- 9) If the person in your community has a disability needs health or rehabilitation services, where would they go and how much would it cost?
- 10) What do you think of the children who have a disability and who go to school in your community?
- 11) What do you think about the work opportunities for adults in the community that have disabilities?
- 12) Tell me what you know regarding the types of machines that exist to help those with disabilities.
- 13) Where would a person with a disability get a machine to help them?
- 14) What types of resources would you like to be accessible for those individuals in your community who have a disability?
- 15) What should I have asked you regarding disabilities in your community that I did not ask you?