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## **VULNERABILITY FOR HOUSEHOLDS WITH PERSONS WITH DISABILITIES AND HIV/AIDS IN CHONGWE, ZAMBIA**

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**March 2010**

*This study is made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of American Institutes for Research through Cooperative Agreement DFD-A-00-07-00189-00 and do not necessarily reflect the views of USAID or the United States Government.*

## Executive Summary

Little research has been done to understand the interplay between HIV/AIDS and disability at the household or community level, either nationally or globally. In Zambia, the country of focus of this research, there are no published studies on the prevalence of HIV/AIDS within the population of individuals with disabilities, and to further complicate matters, no firm data on the prevalence of disability in the Zambian population. Despite the paucity of research linking HIV/AIDS and disability, it is believed that barriers and discrimination faced by people with disabilities, and especially by women with disabilities, reinforce the drivers of HIV/AIDS and poverty in ways that influence and even exacerbate household vulnerability.

The ENGAGE project, implemented by the American Institutes for Research and funded by US Agency for International Development, is working in Zambia in partnership with a program led by World Vision (WV) called Reaching HIV/AIDS Affected People with Integrated Development and Support (RAPIDS) to introduce a disability dimension in a “mainstream” HIV/AIDS program. The ENGAGE and RAPIDS teams determined that in order to define how to address disability within the context of a large HIV/AIDS project, it was first necessary and appropriate to research the interplay between disability and HIV/AIDS at the community and household level.

This pilot study, which focused in the Chongwe district, 60 kilometers outside the capital of Lusaka, found that disability was present in over 35.7 percent of HIV/AIDS vulnerable households and that people with disabilities were less likely than their non-disabled peers to seek care and support from hospitals and clinics, to attend school, or engage in productive economic activities.

The study also found that vulnerability and household response behaviors are bidirectional. For example - primary caregivers are often burdened with their responsibilities, but are nevertheless in positions of power in the household. Similarly, individuals with often need the care provided by caregivers, and as a result of the relationship with the caregiver and their disability are less independent. The relationship with the caregiver – characterized by power in one direction and dependency in the other – can also render an individual with a disability, at times, more vulnerable to abuse and/or neglect.

This pilot study is only the first of many necessary steps to understand the complex and little researched relationship between HIV/AIDS and disability.

### *Key Findings*

- 92 people from a randomized sample of 235 households and 1,089 people receiving support from RAPIDS in Chongwe were identified as living with a disability. Of these
  - 33 have physical impairments
  - 30 have neurological disabilities – including 27 epileptics
  - 16 have visual impairments
  - 7 have intellectual/mental disabilities
  - 5 have hearing impairments
  - 1 is characterized as having an “other” type of disability

- 56.6 percent of the 92 people sought care and support related to their disability from government hospitals or clinics, while 22 percent of persons with disabilities did not seek care or know that care exists and over three percent seeking care from traditional healers.
- More than half of the youth with disabilities were not in school (28 individuals of the 52 who were under age 20) and did not have access to regular educational opportunities. In addition, 14 children and youth with disabilities were not living with an immediate family member.
- A greater percent of non-disabled people sought care for illnesses than their disabled peers. Three-quarters of non-disabled individuals with illnesses sought care in the previous three months, while two-thirds of persons with disabilities sought care for illness in the same period.

Through household interviews and focus groups, people with disabilities, primary caregivers and voluntary community caregivers all expressed a desire for additional support and training for people with disabilities. People with disabilities responded that they want support so they can increase their self-sufficiency, have greater access to education and income generating activities, and so they can more meaningfully participate in their households and communities. The following types of support were identified by those surveyed:

- Assistive devices to allow for greater mobility including wheel chairs, adaptive bicycles;
- Physical therapy and other rehabilitation services designed to increase independence;
- Adaptation of household and community resources including water and sanitation points and schools;
- Training in self-care; and
- Access to education and job training to contribute to the economics of the household.

#### *Recommendations for Development Assistance Organizations*

This study reinforces that those who design and implement development assistance programs must address the needs of individuals with disabilities within the context of those programs. For example, if disability is ignored by development assistance, household vulnerability can be exacerbated, caregivers overwhelmed, and poverty deepened. As this research indicates, families and caregivers make choices regarding which family members receive assistance or have access to health care, education, and work opportunities. The fact that people with disabilities have less access to things that can help them means that they are more dependent upon caregivers than other family members. It also suggests that they add to that family's vulnerability. Their dependent status also makes the person with the disability in the household more vulnerable to neglect and/or abuse.

This research also indicates that disability takes many forms within a community, requiring development assistance organizations to acquire a nuanced understanding of how disability manifests itself, and how access to quality services can assist people with different types of disabilities overcome barriers and become more self-sufficient. The research also found that

lay people – in this instance volunteer community caregivers – have stereo-typical views of disability that can themselves add to the barriers faced by people with disabilities.

To overcome and address these issues, development professionals working on HIV/AIDS and other issues must acknowledge that disability exists and address it as a human rights issue which if ignored, contributes to poverty and vulnerability. Development assistance providers must also recognize that if they do not understand the nuances of disability, they must seek out and establish partnerships with the leaders of disability rights organizations and disability professionals to ensure that programs are appropriately designed and implemented.

### *Recommendations for Research*

This study also highlights the need for further research to understand the complex nature of disability and HIV/AIDS's impact on households in Chongwe, Zambia and around the world. From an advocacy point of view, research is needed to drive funding. From a programmatic point of view, additional research is needed to better understand how disability affects overall vulnerability and contributes to poverty. The following research strategies are recommended:

- Large scale, randomized and rigorous assessment of HIV/AIDS and disability prevalence with professional public health experts, social scientists, anthropologists, and disability experts and advocates;
- Understanding individual perceptions around disability as a result of HIV/AIDS and other illnesses versus disability from childhood;
- Deeper exploration into the differences in care seeking behavior for persons with disabilities and for non-disabled persons;
- Access to services and education for person with disabilities on sexual and reproductive health education and the related services;
- Research to better understand why and how persons with disabilities seek assistance from traditional healers;
- Research issues of resentment: households of non-disabled persons or non-HIV/AIDS affected and the issues of resentfulness regarding the assistance provided to those households with a disability;
- Impact research on small grants for income generation activities among persons with disabilities: small holder farming, livestock, knitting; and
- Experiences, impact and needs of individuals disabled as a result of HIV/AIDS.

Understanding the complex needs and finding ways to actively involve persons with disabilities in HIV prevention, resource mobilization and activity planning is essential to achieve the Millennium Development Goals (MDGs), fulfill the objectives of the Zambia Poverty Reduction Strategy, and comply with the UN Convention on the Rights of Persons with Disabilities.



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## Acronyms

AIDS	Acquired Immune Deficiency Syndrome
AIR	American Institutes for Research
ART	Anti-retroviral Therapy
CBO	Community Based Organization
DHS	Demographic Health Survey
EFA	Education for All
ENGAGE	Engaging Disabled Persons Organizations in International Development
FBO	Faith Based Organization
GRZ	Government of the Republic of Zambia
HIV	Human Immunodeficiency Virus
M&E	Monitoring and Evaluation
MDG	Millennium Development Goals
NGO	Non Governmental Organization
OVC	Orphans and Vulnerable Children
PLWHA	Persons Living with HIV/AIDS
RAPIDS	Reaching HIV/AIDS Affected People with Integrated Development and Support
SINTEF	Foundation for Scientific and Industrial Research at the Norwegian Institute of Technology
SPSS	Statistical Package for Social Sciences
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNESCO	United Nations Economic and Social Council
UNICEF	United Nations Children’s Fund
USAID	United States Agency for International Development
VCC	Voluntary Community Caregivers
WHO	World Health Organization
WV	World Vision
ZAFOD	Zambian Federation of Disability Organization



## Introduction

Little research has been done on the interplay between HIV/AIDS and disability at the household, community or national levels in Zambia or internationally. The complex dynamic between HIV/AIDS, disability and poverty in Sub-Saharan Africa requires a more thorough look in order to better understand how these conditions may reinforce one another. Limited statistics are available on disability in Zambia and there are no published studies on the prevalence of HIV/AIDS within the disabled population within the country. Despite the paucity of research linking HIV/AIDS and disability, it is believed that local perceptions of disability and gender, coupled with the social, cultural and economic drivers of HIV/AIDS and poverty, impacts persons with disabilities and reinforces the drivers of HIV/AIDS and poverty to influence household vulnerability.

Many issues compound when a household simultaneously confronts having one or more persons living with a disability *and* one or more persons living with HIV or AIDS (PLWHA). Each day, households and communities are forced to make difficult trade-offs to provide support to members and satisfy their respective needs. For households with persons with disabilities and PLWHA, the costs and time needed to provide continuing care can make these trade-offs even more severe, impacting the entire household and complicating the household and community's long-term poverty reduction activities.

This pilot study was undertaken to better understand how households fare when they contain both members who have HIV/AIDS and members who have a disability. The findings, perhaps not surprisingly, show that the answer is complex when vulnerability and resource management depends on more variables than just the presence of disability and/or HIV/AIDS. To be noted at the outset, while HIV/AIDS has many disabling outcomes, specifically targeted in this study were households where one or more members had HIV or AIDS and one or more members had a pre-existing disabling condition, irrespective of whether these persons with disabilities might also be HIV+ or have AIDS.

The study found that vulnerability and household response behaviors are bidirectional. Primary caregivers serve as the lynchpin of daily household activities, and thus have power over others in the household but these members are nevertheless burdened by their responsibilities. These primary caregivers have articulated concerns about the long-term prospects of the person with a disability over and above the other household members. In addition, persons with disabilities show concern and frustration regarding their ability to meaningfully contribute to the household and to reduce the burden on the primary caregiver, but at the same time dependent on that caregiver – a dependency which may leave them vulnerable to abuse and/or neglect.

Persons with disabilities interviewed as part of this research have called for the increased availability of support services. This support includes greater access to assistive devices that will promote greater physical mobility, such as wheelchairs and adaptive bicycles, as well as access

to physical therapy (physio) and other rehabilitation services designed to increase independence. Persons with disability also called for the adaptation of households and community resources including water and sanitation points, as well as training in self-care, and education and job training opportunities as persons with disabilities were more often to not be in school or engaged in economic activities.

### **Challenges and Opportunities**

The primary objective of this pilot study was to understand the profile of disability issues within a generalized HIV/AIDS epidemic. There is little research and even fewer resources available to undertake a rigorous assessment of disability in HIV/AIDS affected communities and vice versa. The Engaging Disabled Persons Organizations in International Development (ENGAGE) project at the American Institutes for Research (AIR) funded through the US Agency for International Development (USAID) attempts to involve persons with disabilities in a strategic and inclusive manner in international development activities. In the Zambian context with a generalized HIV/AIDS epidemic, including persons with disabilities requires understanding disability in terms of HIV/AIDS and how this dual relationship plays upon household vulnerability. However, due to the limited available research, AIR, through its strategic partnership with World Vision's Reaching HIV/AIDS Affected People with Integrated Development and Support (RAPIDS) determined that it was necessary and appropriate to understand the interplay between disability and HIV/AIDS at the community and household level.

This pilot study is only the first of many necessary steps in understanding the complex and little researched relationship between HIV/AIDS and disability. Limited financial and human capacity resources required AIR and WV-RAPIDS to utilize proxy indicators and volunteer staff in order to manage and collect the data. As a result, 92 people from a randomized sample of households receiving support from RAPIDS in Chongwe were identified as living with a disability. A large scale, randomized and rigorous assessment of HIV/AIDS and disability will require professional data collectors, anthropologists, disability specialists, and evaluation experts. This pilot study was undertaken in the hope that the findings would provide a basic understanding of the link between disability and HIV/AIDS, inform implementers on the need to understand and include persons with disabilities in program design and implementation and to provide a road map for needed future research and to begin the dialogue with stakeholders.

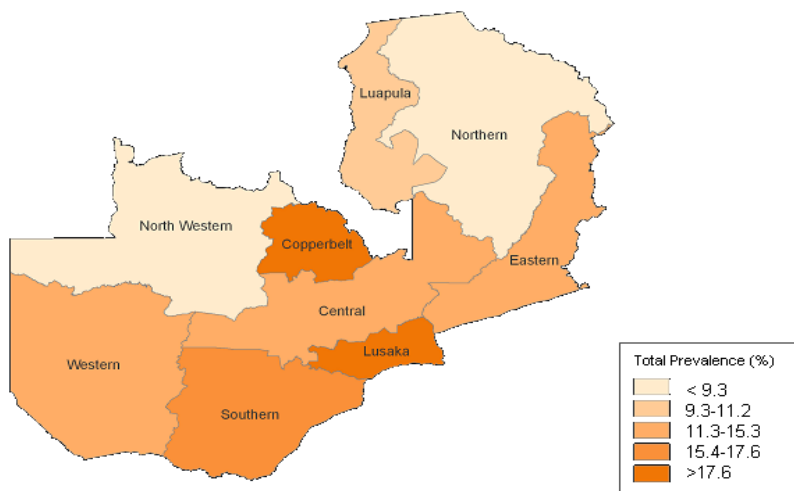
### **Background**

HIV/AIDS prevention, testing, treatment, care and support activities and research are widespread across Zambia and Sub-Saharan Africa. Research, programming and policy around persons with disabilities are lacking, particularly in countries with a generalized HIV/AIDS epidemic. According to the 2007 Demographic Health Survey (DHS), 14.3 percent of Zambian adults are living with HIV/AIDS (Demographic and Health Survey, 2009). Based on official mapping from 2002 UNAIDS estimates; HIV/AIDS is a generalized epidemic with the highest concentrations in Lusaka, Copperbelt and Southern Province with over 15.4 percent prevalence, see Map 1 (UNAIDS, 2008).

The United Nations, World Health Organization (WHO), the World Bank, and UNAIDS agree that the global disability rate is approximately 10 percent or an estimated 650 million people worldwide, with 80 percent of persons living in developing countries (UNESCO, 2008). It is estimated that 97 percent of persons with disabilities worldwide are illiterate with only 1 percent of disabled women literate (UNESCO, 2008). The 2008 *Education for All (EFA) Monitoring Report* estimates that children with disabilities make up one-third of the 72 million out-of-school children worldwide (Education for All, 2008). To date, the DHS (or other global standards of measure) has not collected explicit data on disability in Zambia or worldwide.

Despite the magnitude of these figures, a lack of rigorous research utilizing a range of definitions of disability and differing research methodologies has resulted in large discrepancies in statistics on disability and prevalence of persons with disabilities from country to country. For example, counter to what one might expect estimates of prevalence ranges from under 1 percent in Kenya to 20 percent in New Zealand (Mont, 2007).

Map 1: Adults (aged 15-49 years) HIV prevalence in Zambia, provincial, population based survey 2002



Central Statistical Office [Zambia], Central Board of Health [Zambia], and ORC Macro, 2003. Demographic Health Survey 2001-2002. UNAIDS, WHO.

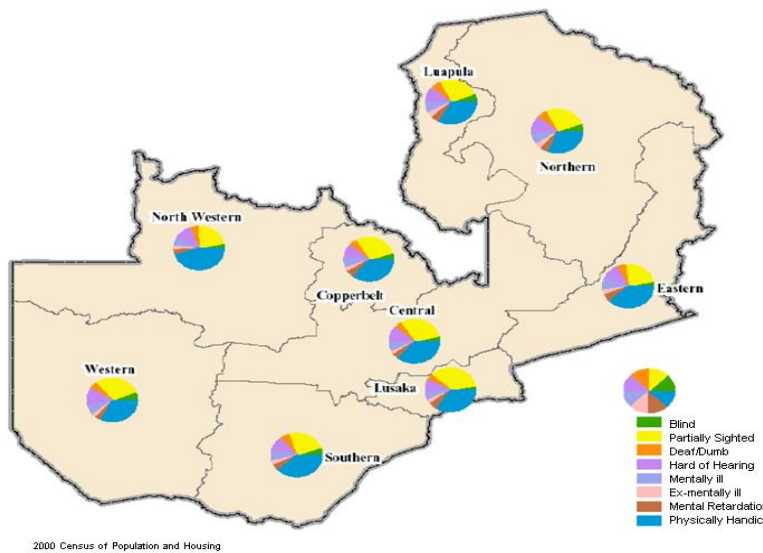


This disparity in rates of disability is reflected in Zambia. The Government of the Republic of Zambia (GRZ) has included disability in its census data since 1969. According to the 2000 Census Data from the Zambia Central Statistical Office, 2.7 percent of the Zambian population is disabled. Among the provinces, Western has the largest proportion of persons with disabilities (3.8 percent), while Lusaka has the least with 1.9 percent. The Central Statistical Office tracks disability related data based on gender, location, type of disability, education and employment. Physical disability is the most common type of disability affecting about 39 percent of persons with disabilities while so-called “ex-mentally ill persons”<sup>1</sup> make up the smallest proportion at four percent. About 40 percent of persons with disabilities have never been to school and another 40 percent have completed only primary education. Within all categories, the largest proportions of the persons with disabilities are self-employed with the most common occupation being agriculture, making up about 81 percent (Central Statistical Office, 2000). (See Map 2 for a breakdown of provincial disability classification according to the GRZ in 2000).

<sup>1</sup> The GRZ census defines the ex-mentally ill as people who have received treatment for their mental illness including counseling and medication separate from those individuals actively coping with mental illness.

In contrast, according to the 2006 Foundation for Scientific and Industrial Research at the Norwegian Institute of Technology - SINTEF Health Research Survey, Zambia has a 13.1 percent prevalence of persons with disabilities (Loeb, Eide, & Mont, 2008). The current population estimate for Zambia is around 13 million people. When comparing the UN estimate of 10 percent of the population living with a disability to the SINREF Survey of 13.1 percent, the number of persons with disabilities in Zambia could range from 1.3 million to 1.7 million, respectively. These estimates stand in contrast to the 256,690 persons with disability approximated by the 2000 GRZ Census Data (Central Statistical Office, 2000).

Map 2: Distribution of Disabled Persons by Type of Disability & Province



HIV/AIDS and disability have overlapping stressors. In a country with potentially over 1 million persons with disabilities and a concentrated HIV/AIDS epidemic, the long and short-term ramifications of disability and HIV/AIDS on Zambians could be considerable. However, these numbers fail to illuminate the real impact of AIDS and disability on Zambia as there are many additional non-disabled and non-infected persons directly and indirectly impacted by the presence of disease and disability.

Finally, when compared to many other African countries, Zambia has a positive track record with disability issues, at least on paper. In 1996, the government initiated the Disability Act of 1996 and established the Zambia Agency for Persons with Disabilities. In May 2008, Zambia signed the UN Convention on the Rights of Persons with Disabilities followed in September 2008 with the signing of the Optional Protocol, with full ratification in December 2009. In addition, the Zambian Ministry of Education has created and supports a series of special schools for children with disabilities, while the Zambian National AIDS Commission maintains a disability technical group. Disability is also included in the Zambian Poverty Reduction Strategy Paper alongside groups of other vulnerable people like women, children, and small-scale peasant farmers (Government of the Republic of Zambia, 2002). This grouping, however, does not address the unique risks, needs and opportunities for persons with disabilities in Zambia.

Measuring disability in and across countries is complicated by the fact that there is no single definition of disability. The term not only has multiple constructs, how it is perceived also varies by a country's historical and cultural context. Daniel Mont, from the Disability and Development Team at the World Bank, and Mitchell Loeb and Arne Eide, from SINTEF Health Research, have made the most recent attempt to standardize the methodologies used to

measure the prevalence of disability in Zambia and worldwide, see Text Box 1 (Loeb, Eide, & Mont, 2008).

Measurement of disability is complicated by the fact that there are multiple definitions of disability. Traditionally, disability was defined within a medical model, which links disability to various medical conditions resulting from natural, environmental or clinical incidents. Within the medical model, disability is viewed as a problem or issue residing solely with the individual. Recently, the medical model has been replaced by the social model of disability, which considers disability as it relates to the interactions of a person's functional status within their physical, cultural and policy environments (Shakespeare & Watson, 1997). Neither model captures the complexities of defining the population of persons with disabilities and the constructs of a fully inclusive life. However, the social model supports the assertion that if the environment were designed for the *full range* of human function then persons with disabilities would be able to fully participate in society. Unfortunately, in the resource constrained settings of many developing countries, access to medical, health and social services for persons with disabilities can be lacking. The highest manifestation of the social model assumes that people have access to extensive medical, educational, physical and human resources and can utilize these services as desired or necessary. In reality, many people with disabilities live in developing countries with limited availability of or access to complex social and health services. The absence of health services can prolong or exacerbate a disabling condition, further limiting participation in society. In some instances, access to simple low-cost medical interventions and health services could all but eliminate disabling conditions, like cataracts, cleft pallet, or making basic eye glasses available.

**Text Box 1: Definition of Disability**

Disability measurement tools can produce starkly different prevalence rates. A comprehensive approach includes:

- Self-identification as disabled
- Diagnosable conditions
- Activities of daily living
- Instrumental activities of daily living
- Participation

However, there are different definitions and classifications within these categories that can produce varying prevalence rates.

Regardless, persons with disabilities make up a considerable portion of the world's poor.

In both the developed and developing countries, evidence suggests that persons with disabilities are disproportionately represented among the world's poor and tend to be poorer than their counterparts without disabilities. It is estimated that of the world's poorest people, meaning those who live on less than one dollar a day and lack access to basic necessities such as clean water, food, clothing and shelter, 1 in 5 is a person with a disability (UNESCO, 2008).

The World Bank estimates that persons with disabilities make up 20 percent of the world's poor due to limited education and employment opportunities (Elwan, 1999). Research has shown that when confronted by social and economic shocks and stressors, households disburse assets rapidly in the short-term, but will recover over time. When multiple stressors impact households, they are not as resilient and are less likely to recover over time. With limited

coping mechanisms, these overstressed households are also less likely to be able to respond effectively, in the short-term or the long-term, to the adverse impacts that HIV/AIDS or disability often have on household resources. In a World Bank Report, Ann Elwan finds a strong bidirectional link between poverty and disability, especially in developing countries. For while poverty can increase disability rates due to poor nutrition, limited access to health services and adverse conditions, disability can also increase rates of poverty through lower rates of literacy, malnutrition, few immunizations, and lower birthrates as well as limited access to and flexibility in employment (Elwan, 1999).

This link between poverty and disability has been well documented and it is widely recognized that poverty causes disability and disability causes poverty, particularly in resource limited settings. The presence of disability can trap individuals and entire families in a life of poverty due to the barriers persons with disabilities face in education, employment and social inclusion (Mont, 2007). According to Mont, Elwan, Groce and others, such cycles of poverty may be further compounded when some persons with disabilities and their family members (similar to other highly impoverished and marginalized populations) are forced to undertake or are subject to risky behaviors, such as unsafe work or trading sexual favors for food or money in order to satisfy their basic needs, thus increasing their risk of exposure to HIV. Extreme poverty also means such individuals and families are also at increased risk of secondary disabilities, through inability to afford or access health care, increased child mortality, and deterioration in maternal health gains. Persons with disabilities are often excluded from HIV/AIDS and other health education and prevention activities, thereby further increasing the incidence of other diseases and reinforcing the drivers of poverty.

The emerging body of the research available on the relationship between disability and HIV/AIDS began in the wake of the 2004 *Global Survey on HIV/AIDS and Disability* by the World Bank/Yale University, which compiled responses from 57 countries and determined that the AIDS epidemic has been largely unrecognized among both disability and AIDS outreach and advocacy groups (Groce, Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts, 2006). The survey also concluded that not only are some sub-groups at a greater risk for HIV/AIDS, all persons with disabilities have the same or greater risk for all HIV/AIDS risk factors. Therefore, individuals with disabilities must be included in all AIDS outreach and advocacy efforts (Yousafzai & Edwards, 2004).

The growing body of research not only confirms that persons with disabilities are at risk but increasingly focused on the impact of HIV/AIDS in their lives and within their families (Groce, HIV/AIDS and Disability, 2005). Recent research from South Africa bolsters these findings by reporting that the discrimination and spread of HIV/AIDS amongst persons with disabilities has been made worse by the fact that they are often perceived as asexual and incapable of having sexual relationships (South African National AIDS Council, 2008). A recent systematic review of disability and HIV/AIDS literature from across Africa by Jill Hanass-Hancock describes the available research on the sexuality of persons with disabilities, particularly that persons with disabilities are sexually active and according to research revealed that 76 percent in Malawi, 80 percent in Cameroon and 89 percent in Kenya were sexually active (Hanass-Hancock, 2009).

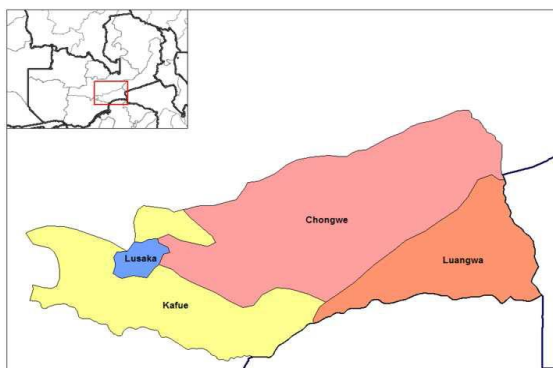
Women and girls with disabilities are often at increased risk of sexual and gender based violence, injury or abuse, neglect or negligent treatment, discrimination, maltreatment, or exploitation (Hayes, 2007). “Sexual exploitation and abuse were believed to be higher among disabled women than their non-disabled peers because the former are perceived to be “free” from the HIV virus” (Yousafzai, Dlamini, Groce, & Wirz, 2004). Although the research begins to highlight the risk factors for person with disability related to HIV/AIDS, what has not been examined before is the *indirect* impact that the HIV/AIDS epidemic is having on persons with disabilities and their families when household time, attention and resources must be divided between supporting persons with disabilities and supporting other family members who are HIV+ or living with AIDS.

## Methodology

This study seeks to better understand the interplay between disability and HIV/AIDS and its impact on wellbeing at the household and community level. The research was conducted in partnership with RAPIDS, a USAID funded consortium of six NGO’s: World Vision (lead agency), Africare, CARE International, Catholic Relief Services, Expanded Church Response, and the Salvation Army. The RAPIDS Project has trained and equipped 19,839 caregivers to provide care and support to 258,812 OVC, 65,790 PLWHA, and prevention for 98,467 youth in 52 of Zambia's 72 districts. RAPIDS has an expansive network that allowed the study to target communities and households already identified as HIV/AIDS affected. In addition, RAPIDS’s mission is grounded in the notion that while HIV and AIDS may *infect* individuals, it also *affects* households. Having access to the HIV/AIDS affected households through RAPIDS provided a gateway for researchers to identify households and communities affected by both HIV/AIDS within the RAPIDS matrix as what happens to individuals with pre-existing disabilities in the context of such households.

The RAPIDS program serves poor rural and peri-urban households where one or more persons are HIV+ or have AIDS. Such households receive services from the RAPIDS program because they have significant physical, social and/or economic needs related to HIV/AIDS. Because RAPIDS is a household rather than an individual centered support project with caregivers working within the household, it is possible to work with RAPIDS Voluntary Community

Map 3: Chongwe District in Lusaka Province



Caregivers (VCC) to identify households served that included both disabled and HIV+ members. Consequently, RAPIDS could quickly identify households with HIV/AIDS and disability that were willing to participate in this study. The presence of a person with a disability in an already struggling household may lead to additional needs. RAPIDS experience working these households was an asset in the identification of overlapping variables between HIV/AIDS and disability.

The mixed method study, involving a demographic style survey, focus groups with caregivers and household interviews and was conducted in three phases in the Chongwe District in the Lusaka Province. Chongwe is one of four districts of Lusaka Province in Zambia. It is located about 60 kilometers outside of Lusaka city, roughly 10,500 square kilometers (ICLEI, 2008). With a population of 137,461, according to the 2000 Census of Population and Housing, Chongwe has a population density ranging from 17.9 to 45.7 people per square km (Central Statistical Office, 2000). The population primarily speaks Nyanja, Soli and some English.

The limited resources available and considerable need for in-kind support from various people and organizations, required the study design to utilize various proxy sources for data collection, like the RAPIDS VCCs. Technical field staff to undertake the interviews and manage the data collection was provided by RAPIDS with ENGAGE working in partnership with the RAPIDS team in Zambia to provide systematic oversight of the data collection process, as well as data entry and data analysis of segments of the study. This study attempts to take a snapshot of disability and HIV/AIDS at the household level through the three data collection tools:

1. Demographic style survey,
2. Focus groups and
3. Household level interviews.

These data collection tools received clearance from the AIR independent Institutional Review Board and were submitted to and approved by the University of Zambia: Biomedical Research Ethics Committee. This snapshot hopes to illustrate the complex nature of vulnerability of HIV/AIDS and disability on households and the need for further rigorous research to validate these initial observations.

Phase 1: The demographic style survey consisted of collecting demographic information through closed-ended coded questions on 235 RAPIDS selected HIV/AIDS and disability impacted households. Through a random sampling of the 405 VCCs working in Chongwe, 89 VCCs opted to participate in the study providing household demographic data for all members of their client-households, including age, gender, current education or economic activity, self-identifiable disability, care seeking behavior, and recent and chronic illnesses. Self-identification of disability was collected in five areas, intellectual disabilities, hearing impairment, neurological disabilities, physical impairment, and visual impairment and then further disaggregated to 17 sub-categories.

**Table 1: Disability Categories and sub-Categories**

Intellectual Disabilities	Neurological Disabilities	Physical Impairments	Hearing Impairments	Visual Impairments
Mental	Cerebral Palsy	Partial Paralysis	Deaf	Blind
Intellectual	Epilepsy	Full Paralysis	Hearing	Visually
	Developmental Delay: Physical/Neurologic	Limited Mobility	Impaired	Impaired
		Restricted Mobility		
		Amputee: Arm/Hand		
		Amputee: Leg/Foot		
		Dwarfism		
		Functionally Disabled		



The RAPIDS Monitoring and Evaluation (M&E) personnel served as data collectors due to the complex nature of disability and the confidentiality issues related to the RAPIDS households. On average, the participating VCCs provide support to three households each, providing the study with 235 households ensuring demographic style information collection on entire households (i.e. adults, children, males, females, immediate family, extended family, healthy, ill, etc.) over a three-week period in April 2009. The survey tool was based on a portion of the annual World Vision Zambia Sentinel Survey and developed under the direction of the RAPIDS M&E personnel, Nora Groce from the University College London and the ENGAGE team at AIR.

Phase 2: Two focus groups of VCCs, with ten participants each were held in July 2009 in Chongwe. The focus groups were conducted using open-ended questions on the interplay between disability and HIV/AIDS effect on households that has both an individual living with HIV/AIDS and a person with a disability. Topics discussed included asking the VCCs how they spend their time supporting households, how do they prioritize their support activities within the targeted households, their observations of disability and illness within each household and the community, and their concerns and needs related to training and support for the persons with living with disabilities in their client-households. The questions were designed to create a dialogue and participants were encouraged to expand upon remarks and add input they believed relevant to the condition of households with which they work.

Phase 3: Based on the Phase 1 data collection, 33 households were selected for in-depth interviews with primary household caregivers as well as with the person living with the disability within the household. The households were selected from the demographic survey based on the identified disabilities for each participant. In order for the interviews to reflect a broad range experiences and perceptions, participants were selected to ensure diversity based on gender and identified disability, including persons living with a visual impairment, neurological disabilities (cerebral palsy and epilepsy), mobility issues, and development delays.

Household interviews were conducted using closed and open-ended questions to obtain information on the relationship between disability and HIV/AIDS and its impacts on the household. The interviews concentrated on identifying what a day in the life of such a household actually entails, including activities of daily living, participation in community activities, as well as daily routines where disability and HIV/AIDS intersect with other social and economic demands. The survey tools were developed under the direction of the RAPIDS M&E personnel and the ENGAGE team and validated through pilot testing in the Chanda district with bi-directional translation.

The household interview began with a demographic style data collection section to crosscheck the household composition with the original demographic information collected in Phase 1 to ensure accuracy. Separate components of the survey tool targeted the primary caregiver and the person living with the disability in order to understand the different activities, motivations, perceptions, and experiences of the primary caregiver and the person living with the disability. The interviews were conducted separately when possible in order to elicit candid responses from both interviewees. Trained local Zambian disability specialists conducted the interviews in

Nyanja in order to ensure the appropriate context and terminology was elicited regarding the complex issues related to disability. The disability specialists received data collection training from the RAPIDS M&E personnel and the ENGAGE team at the outset and provided monitoring and consultation throughout the process.

Following the demographic style survey, data was collected and analyzed by AIR using Statistical Package for Social Sciences (SPSS). Due to the small, stratified sample, the quantitative analysis used simple descriptive statistics because of the limited sample size of the completed survey forms. The focus groups and in-depth household surveys were transcribed and translated in Zambia and analyzed by AIR using “theme content analysis” to determine common themes, attitudes and behaviors. As a result of the limitations mentioned, use of qualitative analysis software was not practical. Focus groups and household interviews were compared across participants for common themes and observations. The anticipated small sample size, did allow for direct comparisons but the limited number of subjects hindered definitive analysis based on best research practices. Despite the limitations, a variety of themes emerged that provides a first look at the vulnerabilities and opportunities available to households with persons with disabilities and PLWHA.

### Study Limitations

While the Technical Staff/Field Workers were trained and overseen in the field, there was some deviation from the established survey tools as individuals expanded on questions outlined in the written format or failed to fill in all questions systematically. This limits the size of the sample that can be used for descriptive statistics, as there are problems with comparability between questions. Also, certain issues such as discussions with minors on sexual activity or illegal sexual activity with individuals with mental or intellectual disabilities were limited and constrained. However, the responses and observations of all study participants provided a diverse perspective on the intersection of HIV/AIDS and disability within households in Chongwe with common themes emerging.

### Results

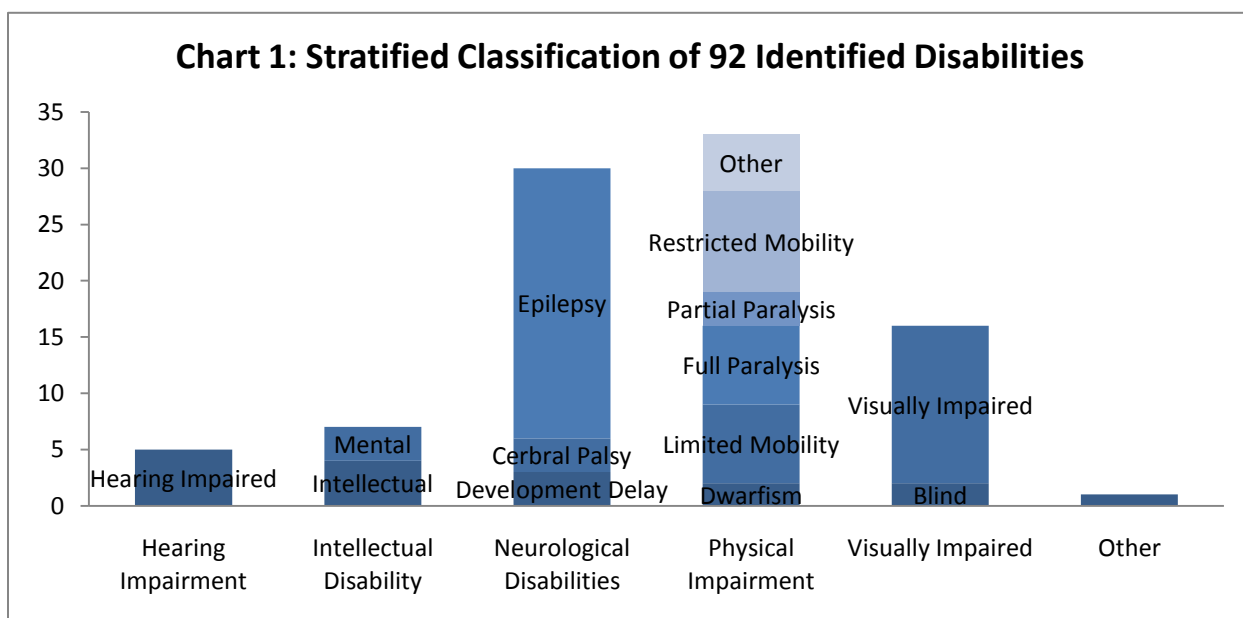
The primary purpose of the study was to understand the impact of the so-called “dual burden” of HIV/AIDS and disability on the daily lives of households in the Chongwe District. However, it also produced an opportunity to understand community needs and beliefs about disability. As RAPIDS serves communities and households based on their perceived or known HIV/AIDS status, the data was collected from households which have one or more members who are presumed to be living with HIV/AIDS even though only 93 PWLHA self-identified in the demographic survey. Lack of persons declaring their HIV/AIDS status is common and likely motivated by the traditional under-reporting of status

**Table 2: Breakdown of the 92 Identified Disabilities**

Primary Categories of Disability	# of Identified Disabilities
Intellectual/Mental	7
Hearing Impairment	5
Neurological Disabilities	30
Physical Impairment	33
Visual Impairment	16
Other (not specified)	1

for reasons of fear, stigma, discrimination, and lack of actual confirmed sero-status. Despite the limited number of reported PLWHA, the methodology employed by RAPIDS in the selection of communities and households to receive support, allows this study to assert that the households included in this study were households living with one or more HIV+ or AIDS members. Within the dynamic of these RAPIDS households, VCC were asked to identify those households with one or more members who had an existing, non-AIDS related disability in one of the five categories listed in Table 2.

The Phase 1: The demographic style survey allowed caregivers to report on disability in regards to overall individual health status not related to their disabling condition and aspects of empowerment and inclusion based on a social model of disability. The health status questions captured commonly understood recent and chronic illnesses and disability status. Questions also probed care and assistance seeking behaviors (access, availability, cost), productive activities within the community (education, productive/economic opportunities) and materials and services for persons with disabilities. Demographic style information was collected on 1,089 people from 235 households across Chongwe. The target population on which data was obtained comprised of 54 percent women and 46 percent men, ranging from less than one year of age to 85 years of age. Based on the self-identification and without external medical or clinical confirmation, 92 people were identified as living with a disability, resulting in an estimated disability presence in Chongwe of 8.45 percent among HIV/AIDS affected households within the RAPIDS populations. (It should be noted that this was far higher than the 2.7 percent estimated by the GRZ and less than the 10 percent of the WHO estimate.<sup>2</sup>) Eleven people were identified as having more than one disability, with eight of the eleven representing dual neurological and intellectual disabilities. The 92 identified persons with disabilities reside in 35.7 percent or 84 of the 235 households surveyed.



<sup>2</sup> As the target population for the study is a RAPIDS community with PLWHA, this study cannot directly relate the 8.4 percent to the Chongwe population as a whole.

The most commonly reported types of disabilities were neurological and mobility related disabilities, while the least reported disability was hearing impairment. See Chart 1 for the breakdown of the 92 people identified as living with a disability.

### *Portrait of Epilepsy*

Children with epilepsy are more likely to be stigmatized. Although this study did not focus on the stigma specifically associated with epilepsy, or other seizure disorder, anecdotal evidence and experience from RAPIDS and World Vision, shows that children with epilepsy experience considerable stigma and discrimination. High levels of myths and misconceptions attached to epilepsy may fuel the high levels of stigma. In addition, many epileptic children are not on treatment (anti-seizure drugs are generally available in district hospitals, clinics and medical stores).

In Chongwe, 27 people were identified as living with epilepsy, or other seizure disorder, with 23 between 5 and 20 years of age. When a child with epilepsy has a seizure at school, the likelihood that the child will stop attending school is very high due to lack of understanding by teachers and existing stigma. Only eight of the 23 youth between 5 and 20 years of age living with epilepsy are in school or receive access to education. Three children interviewed through the household survey stopped going to school after having a seizure at school. Teachers express ignorance regarding medication and perceive epilepsy to be contagious and thus do not support epileptic students or dispel myths.

Physical environment is also an issue for epileptics beyond stigma. Primary caregivers or persons with epilepsy themselves have not been educated or empowered to make their physical environment safer. Water points and latrines remain the highest danger, apart from objects left lying within the household public spaces where these persons live. Most wells are open and runaway water collection is unprotected creating hazards for epileptics as well as other persons with disabilities.



**Unsecured well near households with persons with epilepsy**

In World Vision's Child Health and Education programs there are few records on epileptic children in their activities receiving appropriate care and support. Specialized organizations like the Epilepsy Association of Zambia or the Ministry of Education can be targeted for partnerships to provide support to households with epileptic children. Without access to education and basic services, epileptic children and ultimately their families have increased vulnerabilities and limited access to poverty reduction opportunities.

Physical impairment included various levels of paralysis, mobility issues, and missing limbs. Visually impaired includes the spectrum from completely blind to various visual deficits. Neurological disabilities included epilepsy, cerebral palsy and development delays. The high number of epileptics (27) and young persons under 40 years of age with visual impairment (10 of 16), requires further investigation to generate greater understanding of the environmental factors that may result in such numbers. (See Portrait of Epilepsy.)

### **Prioritizing Support *within* Households**

Households with both disability and HIV/AIDS have a complex dynamic with compounding needs and competing priorities for allocation of resources. This study anticipated that households with persons with disabilities would have greater challenges and therefore a clear pattern of how they would determine resource allocation both human and financial. In actuality, this study found no easily discernable patterns as prioritizing resources occurred on a day-by-day and situation-by-situation basis.

Primary caregivers serve as the lynchpin of these vulnerable households providing care and support to persons with disabilities and PLWHA. When questioned primary caregivers and VCCs indicated similar issues in prioritizing support but no clear patterns emerged. Persons with disabilities were consistently and keenly aware of the stressors on the primary caregiver and the household and wanted to be more self-sufficient. Many note that if given certain resources then many persons with disabilities would be able to substantially contribute to the household and reduce the burden on the primary caregiver as well as maintain a degree of personal autonomy and independence.

As social safety nets are stretched as a result of poverty, HIV/AIDS and other stressors on the communities and households, many households have absorbed extended family and friends. In the target population in Chongwe, almost one-third of the households surveyed absorbed non-immediate family members, therefore requiring additional resources to support all household members including costs associated with food, shelter, education, and health care. Thirty-eight households have both a person living with a disability and have absorbed a non-immediate family member. Allocating resources in these complex-extended households falls to the already over burdened primary caregiver.

In activities of daily living, nearly half of persons with disabilities were not in school or engaged in economic activities and those with neurological disabilities nearly two-thirds were neither working nor in school compared to only one-quarter of the interviewed general population in Chongwe. Overall, persons with physical impairments were more likely to attend school or engage in economic activities at over two-thirds. However, the persons with other disabilities lack of access to education reduces the long-term opportunities to actively contribute to the household, as their economic opportunities are limited due to lack of literacy and numeracy.

Many primary caregivers and persons living with disabilities mentioned that if the person with the disability could receive treatment or assistive devices like wheelchairs that it would improve their individual and collective condition, however funds are not available for treatment,

materials, or knowledge of the availability of services and support related to their disability. The desire for mobility was a primary concern for both the primary caregiver and the person with the disability thus wheelchairs were the most commonly requested commodity (after training) among survey participants. Being able to support and participate in one's family in a meaningful way is among the highest priority.

*Peter,<sup>3</sup> who is blind, feels responsible for caring for his family, but cannot. He relies on his children and wife to care for him and wishes that they could get ahead and that his children could attend school. Peter hopes that someone might be able to help him with his eyes and ears but has not heard of anyone.*

*Simon, who is physically disabled, has to rely heavily on his children to work in the garden and make and transport charcoal. The children are not as productive as he might be if he was able bodied. The family barely scrapes by. There is no money for fertilizer to bring the farm to scale or to pay for things like school shoes, blankets and clothes. He believes there may be help from organizations but has not seen any.*

However, educational opportunities and mobility for persons with disabilities were not the only limiting factors in relation to the desire to meaningfully contribute to their households. Access to health services and issues of sustained illnesses for persons with disabilities, PLWHA and other chronic ailments compounded the human and financial resources of primary caregivers and households as a whole. Overall health status has long been associated with economic and productive activities for individuals and households, therefore understanding access and use of health services is necessary to understand the complex circumstances of households and their relative vulnerabilities. Of the surveyed population, over three-quarters of individuals with illnesses, without a disability, had sought care within the previous three months, while two-thirds of individuals with identified disabilities sought care for their illnesses during the same period. Persons with neurological disabilities and physical impairments were four times more likely to seek care than persons with visual, hearing and intellectual disabilities for a recent illness. Prioritizing access to treatment for different people based on illness and disability forces households and individuals to reprioritize resources for the household as a whole potentially creating a conflicting power dynamic between the primary caregiver, the person with the disability and the PLWHA or other ill household member.

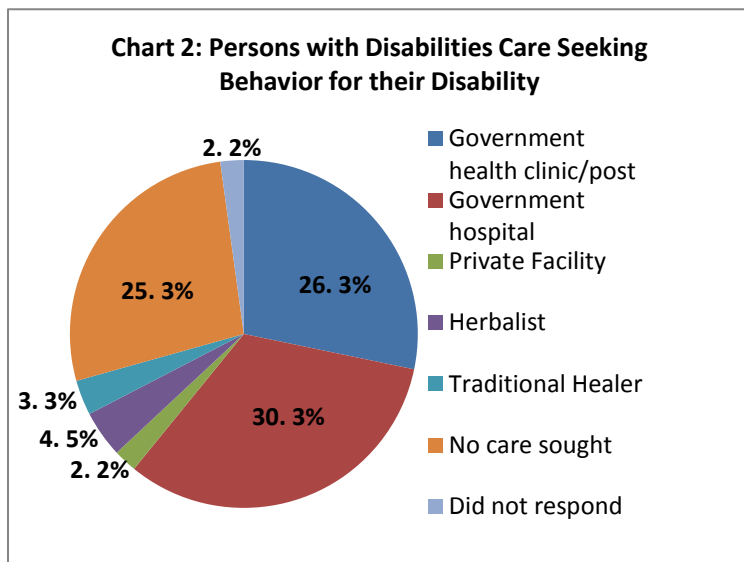
Understanding the availability and use of formal and informal health services was also a key factor in understanding the impact of illness and disability on the household. Individuals with disabilities were less likely to seek medical support for unrelated illnesses than the general population. Of persons with recent illnesses without identified disabilities, 95 people out of 115 (82.6 percent) with declared recent illnesses sought care at the government health clinic/post or government hospital. Meanwhile, only 20 persons with disabilities with a recent illness out of 33 (60.6 percent) with declared recent illnesses sought care at a government facility. Of the sampled population, roughly 6 percent of both individuals with disabilities and non-disabled

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<sup>3</sup> All names have been changed to insure confidentiality.

persons sought care for recent illness from the VCCs or community health workers. Although the demographic data does not address the reason for low use of VCCs and community health workers, the household interviews and the focus groups indicated that the VCCs and the community health workers lack comprehensive training and materials to provide real support on clinical health issues to households and spend more time supporting households in activities of daily living like collecting wood, drawing water and maintaining the grounds.

The numbers are far more varied in terms of targets for care regarding persons with disabilities when it comes to seeking care and support for their disabilities. As demonstrated in Chart 2, 30.3 percent of the 92 persons with disabilities sought care and support related to their



disability from government hospitals and 26.3 percent at government clinics in the previous year. However, unlike non-disabled persons, individuals with disabilities also sought care and support from traditional healers and herbalists. No individuals from the sampled population without a disability indicated seeking care and support from traditional healers or herbalists for recent or chronic illness.<sup>4</sup> Twenty-one persons with disabilities did not seek or know where care and support existed for their disability or basic healthcare.

In one Focus Group, VCCs indicated that persons with disabilities seemed more comfortable with traditional healers and herbalists because they believe that facilities to help them with their disability within the formal medical services did not exist and/or that government health services were too costly. Of the people with disabilities, 50 percent did not seek care because the cost of care and/or access to transportation was prohibitive. When care was sought, most persons with disabilities received antibiotics and medication for pain management, 32 percent and 43 percent, respectively. The services sought and received by person with disabilities, when care was sought was limited to basic, inexpensive and short-term responses to stressors, no one indicated care and support for more complex and long-term health and disability related issues. This focus on short-term fixes does not respond to the long-term health or wellness issues of households vulnerable to disability and HIV/AIDS. This finding supports the need to understand the motivation for persons with disabilities and the motivating factors for targets of care related services, to understand individual perception of illness and disability and services cost benefit analysis.

<sup>4</sup> Understanding the utilization of herbalists and traditional healers for persons with disabilities or the general population in regards to medical care was beyond the scope of this study.

As previously mentioned, in the demographic style survey only 93 PLWHA were identified living in 69 households. Of those 69 households, 50 households also had a person living with an identified disability. However, as this is a RAPIDS targeted community, the actual number of PLWHA is likely to be much higher but underreported due to traditional issues related to HIV/AIDS related stigma. Of households identified as having both a person living with HIV or AIDS and a person living with a disability, 98 percent sought care for recent illness or support around disabilities where as households identifying themselves as only having a person with a disability, 30 percent sought care and support regularly. Future studies could be useful in understanding the dynamic of households with both a person with a disability and PLWHA around their motivation for seeking care and support. Understanding the complex nature of care seeking behavior of PLWHA was beyond the design and scope of this exploratory pilot-study. It also proved difficult to illicit useful information from households in terms of PLWHA who became disabled as a result of HIV or AIDS. Future research is necessary to understand this relationship and the impact on the household.

### **Prioritizing Support to Households**

The pilot study found that in Chongwe, like other communities, households with persons living with HIV and AIDS or living with a disability are forced to make trade-offs in order to care for the household as a whole. Despite the small sample size of 33 households and the lack of uniformity of interview questions, the households interviewed shared similar experiences and observations. The concerns expressed by primary caregivers and the persons with disability mirror each other regardless of the disability, gender or age.

The VCC Focus Groups provided the VCCs with the opportunity to discuss and explore the support they provide to households with sick individuals and persons living with disabilities. The RAPIDS VCCs receive regular training on home-based care to assist PLWHA, provide OVC support and assistance to households in activities of daily living. Overall, VCCs showed concern about the persons with disabilities in the households with which they work. They identified small interventions which would make big impacts on peoples' lives (for example, access to wheelchairs and livelihood activities) but they strongly indicated that they did not have the training to provide the appropriate medical, psychological and emotional support to the person with a disability or the families as a whole around issues of disability. Although not stated explicitly, the under lying message from Focus Group 1 was that the families with both sick and disabled members carry a heavy burden. Focus Group 2 expressed a similar concern regarding these households as they observed the added stress felt by primary caregivers and other household members when there is both a person living with AIDS who is chronically ill person and a person with a disability.

Prioritizing care proved challenging for the VCCs. In both Focus Groups, they indicated mixed feelings and experiences. The decision making process for prioritizing care for persons with disabilities and for PLWHA was not strategic but based on weighing day-to-day needs, priorities and resources. All persons interviewed, VCCs, primary caregivers and persons with disabilities, indicated mixed prioritization when it came to care and some support. Some noted that they first provided or sought to support persons with disabilities because PLWHA on anti-retroviral



therapy (ART) are stronger; others mentioned that individuals with disabilities are not sick and can do things on their own so they prioritize the PLWHA. When providing food and other nutritional support, both Focus Groups acknowledged that they give priority to the individuals with HIV/AIDS who were ill as they may have special foods requirements where as the person living with a disability generally does not. The persons with disabilities were consistently anxious to have access to and take advantage of services both related to health services and economic opportunities from the VCCs to reduce the household resource burden and contribute to their households. Either way, balancing these needs puts the person living with the disability and the PLWHA in conflict with the available resources of the VCC.

Much of the time spent by VCCs during household visits was assisting in activities of daily living as these activities are of the greatest use to households affected by HIV/AIDS and disability. Much of this daily living support requires considerable physical strength and stamina proving to be very difficult and labor intensive, as most of the VCCs and the primary caregivers are women. Moving people about requires the VCCs to be patient and gentle. When asked, one VCC stated:

*This is very difficult because sometimes you find that a person you have to visit can't even feed himself. So if there are three of you, one holds the patient, the other one feeds them and the other is wiping the porridge coming from his mouth.*

The VCCs also provide households with encouragement and counseling. One VCC mentioned that they often deal with people who are suicidal and they find themselves providing them with counseling and spiritual support to convince them to have the will to live. These patients often are the ones with little family support and require more time and services from the VCCs:

*It is the families with the problems, because they don't help in anyway, they just sit and wait for the caregivers to come and sweep, wash and fetch firewood for the patients so it is the families with the problem.*

One VCC remarked that they assist household primary caregivers around the house by sweeping, collecting firewood, drawing water, but often the VCCs are required to take responsibility for caring for the whole household, and not just limited to the person targeted for home-based care support.

*The disabled, when you visit them and you find that they are dirty, whether they stay with their mothers or grandmothers; you just get a container and go to draw water and warm it, then give them a bath. We also ask how they are doing...So you leave that house with a happy person [client], even the disabled child also remains happy because you have shown them love.*

One interesting observation noted by both Focus Groups, the VCCs provide more care to orphans than to the household members with disabilities because orphans have no support system and are believed to receive less care and support overall than the persons with disabilities or HIV/AIDS. Several primary caregivers and VCCs observed that some households with a person with a disability received more care and support than households that did not

have a person living with a disability or an AIDS orphan household. This seemed to create mixed feelings of resentment in some communities towards households and individuals with disabilities, persons living with HIV/AIDS or orphans as support from VCCs varied. Further analysis is necessary as this could be a result of mutual misperceptions on the part of the VCCs, the households and the communities as well as geographic distribution of households, services and VCCs.

The commodities and financial and human capital resources available to the VCCs, often dictated levels of support. The VCCs were able to provide households with simple medicines like Paracetamol, take the sick to clinics, help out with household chores (which vary depending on the VCC's gender), provide spiritual support, act as confidants, and advise the disabled to exercise and go to the clinic. Many VCCs stated that they were more likely to provide greater support to the sick through food, medicine, and trips to the clinic than to the person with a disability since maintaining healthy diets for the sick is seen as more important. The VCCs and the primary caregivers strongly asserted that some persons with disabilities would benefit from wheelchairs and other assistive devices but mostly they were only able to provide clothing, food and household supplies as these items are more readily available.

Providing support to individuals and complete households requires more resources and training than is currently available. VCCs request more supplies for their care kits like more batteries for their headlamps, soap, Paracetamol, and basic equipment such as rope to use as a guide for blind person around the homestead. These items, as well as ongoing training on disability, simple rehabilitation activities, and psychosocial support would strengthen the VCCs' ability to support their clients. The observations of the VCCs align with the desires of person living with disabilities; simple support and empowerment related activities to increase independence and contributions to their households for person with disabilities is greatly desired.

### **Activities at the Household Level**

When asked, primary caregivers reported they were often exhausted and sick due to the amount of work they do in order to support the household in general, to undertake income generating activities, and support the healthy, those PLWHA who are chronically ill, household members with general illness, and person with disabilities. When the head of household and/or the primary caregiver is also disabled there is an added burden on the family and on the primary caregiver/person with a disability. When the person with the disability also serves as the primary caregiver, there are greater issues of household vulnerability and the ability to prioritize ongoing and long-term resource planning that makes the trade-offs for time management and materials greater.

Most households with an individual living with a disability receive the bulk of their support from the VCCs only because the household was identified as being affected by HIV/AIDS or other chronic illnesses by the RAPIDS team. Many people reported being concerned about what will happen to their children and family members after they are gone as there is limited community support and few resources available. The desire to outlive the person with the disability was repeatedly expressed as a major concern of primary caregivers. Some primary caregivers and person with disabilities acknowledged receiving support from community members, but this

was not always the case and not a sustainable solution in communities with already stretched security nets.

*Elizabeth cares for her adult daughter Rebecca, who lives in a separate house. Rebecca, who is paralyzed, always gets helped first. Caring for Rebecca takes a lot of time and resources, and Elizabeth goes to the field late because of the extra time needed to care for Rebecca. She is very concerned with what will happen to Rebecca after she dies and would like to know how to better help Rebecca to improve her welfare. Elizabeth believes that Rebecca's life would be better if Rebecca had cattle or a plough so that she could have someone from the village help her make money off of the land.*

*Christine's daughter is five years of age with leg problems resulting from spina bifida that could be corrected by surgery. Christine can only leave to go to the garden to make money when other family members help her. Her other children are chronically sick. She is worried about food for all of her children; in particular Christine is concerned for who will care for her daughter after she has died.*

Providing support within a household with disabled and HIV/AIDS infected members who are ill has been observed by VCCs to take a toll on the primary caregiver and the household in general. Some family members spend so much time caring for other sick and disabled members of their household that they themselves become sick. Daily support provided to the person with the disability includes taking them to the toilet, bathing and dressing them and helping them eat, in addition to all of the other activities that are required of the primary caregiver to run and ensure income to support the household. As observed by the VCCs and the primary caregivers, this level of activity can have negative effects:

*Some primary caregivers are so discouraged and get affected by the sickness of the patient they are taking care of in that they even start looking as if they are the ones who are sick instead of the sick.*

*Charity is the primary caregiver of a family of nine; her husband has vision and hearing problems. She has received no training beyond the basic home based care support provided by the VCC, but cares for her husband by providing him food, water, guiding him. She goes to the field with her husband so he can care for the baby while she works. If she leaves him at the house, she prepares his food ahead of time. Although the children also help care for their father, the burden of caring for the house and cultivating falls all on Charity. This work is having a profound impact on her personal health, she reports being worried and losing weight 'because of the pressure'.*

Although the heavy workload of the primary caregiver does have a considerable personal impact, it also translates to reprioritization and rationing of care and services for the person with the disability. VCCs often find persons with disabilities alone when they visit clients, young and old. When they ask family members why they did not take the disabled person/child with

them to the field or the market, they will say they could not carry them on their back. This is especially true for elderly caregivers.

*“Like in our village, among my clients, there is this family which is headed by a grandmother and there are almost 13 children...Telling you the truth this woman suffers a lot to look after these children.”*

*“The reasons why these children are left alone at home is because they cannot manage to carry them all day.”*

Generally, people do not want to leave their family members with disabilities or HIV/AIDS alone but reality forces them into productive/economic labor. However, the need to make regular trade-offs between economic activities and care for family members puts added stress on the household as a whole. Regardless of the commitment to care for their family member or the necessity of economic activities, household production is reduced and primary caregivers and households are less able to spend time participating in agricultural and other market generated activities or even poverty reductions interventions led by the GRZ, donors and NGOs. The conflict of spending time and resources on needs related to disability and to illness instead of household infrastructure and food forces many people go to great lengths in order to support their households including the illegal home brewing and selling of beer and borrowing money in order to purchase medicines and food.

The complex time and financial constraints on households with both disability and illness force households and primary caregivers to balance competing priorities. The opportunity cost of primary caregivers' time was a big concern - especially relating to loss in productive labor and household production. Families with sick and/or disabled members seemed too often to have fewer people to do productive labor and consequently have less money for food and other expenses including education related fees and medicine, which increases their overall household vulnerability. This seemed to be especially true since care must be given to the sick and disabled over the needs of the non-sick or disabled. For households with persons with chronic illnesses including HIV/AIDS or disabilities that require support for activities of daily living, the necessity to keep a person, usually a child, home throughout the day can have long-term repercussions for the household and the individual by reducing their access to education and long-term economic opportunities.

*Benson is a 65 year old man who is unable to move his legs. He is able to feed, cook and bathe himself but he relies on people to bring him all of the things he needs. Benson does not undertake any productive labor and sits alone most of the day. When he is ill, his 15 year old granddaughter misses school in order to care for him. She also assists her grandmother, when necessary, by cleaning the house and bringing bath water.*

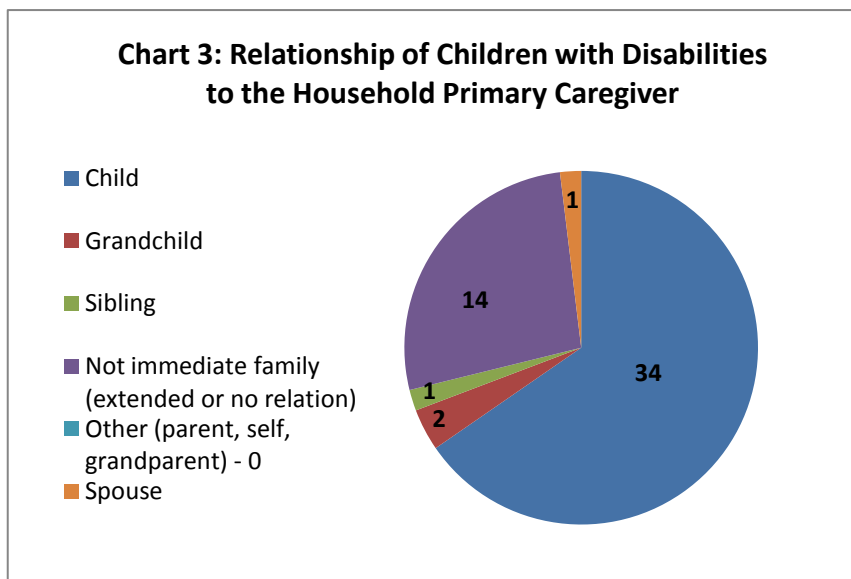
Households have to weigh the costs of goods, services, medicine, education related fees, and food with basic household infrastructure. The need to procure medicine for either and in many cases both the person living with HIV/AIDS and the person living with a disability leads households to have shortages in food for all household members as well as limited resources for

home repairs. Many primary caregivers indicate that they have leaky roofs, which allow the rain and the cold in, making it difficult for the sick to get healthy and to protect the healthy from illness.

### Children and Youth with Disabilities

In addition to the competing challenges of children as temporary or fulltime caregivers for person with disabilities or PLWHA, prioritizing medicine and food over school related fees or keeping children out of school to watch the person with the disability, children living with disabilities have their own set of challenges. Of the 92 identified persons with disabilities in Chongwe, 52 are under 20 years of age. For some, accessing school may require assistive devices such as glasses, hearing aids, orthopedics, other mobility aids, and physical environmental adaptations that are conducive to inclusive learning environments like having accessible classrooms and adaptive toilets.

Most parents or guardian of children with disabilities have little or no understanding their education and medical needs. Often teachers also have limited knowledge or training around inclusion of children with disabilities in the classroom. This lack of awareness forces many children with disabilities to not participate in the educational opportunities that exist in their communities. Access to education is an ongoing challenge for youth with disabilities, of the 52 disabled children identified in Chongwe, more than half (28) are not in school or have not had consistent access to educational opportunities. Education, skills and awareness is necessary to ensure children with disabilities, their parents and caregivers, community health workers, and their teachers all have the appropriate skills for inclusive education, health and socialization opportunities in order to empower children for life.



In resource constrained settings where social safety nets are already strained; individual and household vulnerability increases the pressure on primary caregivers and the daily lives of children. In the Chongwe households with children with disabilities, 14 children and youth are not immediate family members of the household primary caregiver or not related at all.<sup>5</sup> The 2007 DHS found that 19.2 percent of children in Zambia are not living with a biological parent

<sup>5</sup> One youth of 12 years of age identified as a spouse, this relationship could not be confirmed. It is unclear if this was a data collection error or the actual marital status of this individual. Zambian law does not permit the marriage of minors.

(Demographic and Health Survey, 2009), of the surveyed households in Chongwe, these 14 disabled children living with extended family account for 27 percent of the identified disabled children. These 14 children and youth with disabilities may have been abandoned, relocated or possibly orphaned by their immediate family and have been absorbed by extended family members, neighbors or friends. In addition to residing in and receiving care from extended family or neighbors, eight of the fourteen disabled children are not attending school, although two of the eight children are below school age. Regardless of the circumstances of their being absorbed by extended family, it is unclear if these and the other children in these households are able to meet basic material needs. Competing resources for all household members, particularly children influence their short and long-term vulnerabilities and access to health and education services.

### Requests for Training

RAPIDS VCCs receive home based care training on how to care for the sick but have not received training on how to help persons with disabilities. Many VCCs in both Focus Groups stated that they desire more information on how to better identify, feed, move/transport, and care for the disabled. Focus Group 1 expressed profound interest in learning how to better teach disabled persons to do things for themselves that would allow them to care for themselves. This includes learning about rehabilitation exercises to help teach people to walk and undertake household chores. Focus Group 2 hoped for access to wheelchairs, crutches and assistive devices to help person with mobility issues live more fully, which mirrors the desire of people with disabilities and their personal desire to live and contribute more fully. The VCCs perceive a greater level of stigma around people and household with disabilities therefore they indicated a strong need for more knowledge to help support and encourage families and communities and to educate them on how to care for the sick and the disabled as awareness and education will lessen the stigma associated with disability.

In addition to trainings on one-on-one services for clients, Focus Group 2 indicated that they would also like education and materials in order to help fix the physical environment of the homesteads and in the community. Making simple improvements to the environment could reduce the impact of disability on people's lives and increase their participation in the community. Many VCCs believe that with appropriate training and materials, they could support clients in improving the areas where they collect water in particular. Several VCCs expressed an interest in learning sign language so that they could better communicate with their hearing impaired clients.<sup>6</sup>

Despite, these challenges, some caregivers with disabilities are actively involved in providing care to HIV/AIDS affected household. Therefore, involving caregivers with disabilities as frontline advocates, in policy formation, awareness raising, training opportunities, and developmental activities can serve as an approach to the integration of persons with disabilities into wider community participation. Through this, community level participation of caregivers

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<sup>6</sup> Although sign languages skills may be useful in certain environments, in rural settings where the deaf and hearing impaired have not had access to formal schooling or sign language education, the sign language used in these households is unique to the household as it was devised as a way for internal communication.

with disabilities or primary caregivers of households with individuals with disabilities could lead to improved social, environmental and economic inclusion of persons with disabilities overall.

Notably, household primary caregivers, persons with disabilities and persons living with HIV/AIDS all desire training for rehabilitation and income-generating activities in order to reduce the burden on their families and to be self-sufficient.

*Annette's daughter Doris is immobile due to shortened legs; however Doris manages to wash and dress herself and to do her own laundry. She does need help to use the toilet. She knows how to knit but is sad and lonely when she is left alone. Annette is the primary caregiver for a large family and mentioned that carrying the daughter is difficult and that sometimes she cannot farm when Doris is sick. Annette prefers not think about what will happen to her daughter when she is gone, but has made it clear that she believes that financial resources to help her daughter start a business are more important than receiving training in care.*

A standard package of care materials and the reasonable availability of services and assistive devices were the most common requests of VCCs when it comes to providing support to households with disability. Wheelchairs and crutches were the most requested items followed by second-hand clothes and food. Although commodities are necessary, households with sick and disabled persons also need emotional counseling and support. One VCC noted that:

*The cooperation between the families and the caregivers is very important. Because if we do the job of caring for the sick and the disabled together, the burden would be lighter. We need to encourage each other. And if there are any other things that are needed, then some other people will come in and help us.*

Access and availability to productive activities including education and income generation are desired by many individuals and households with individuals living with a disability. Lack of mobility forces many to sit in one place all day. Many of the persons living with the disability have not had the opportunity to go to school because they lacked the ability to get there or lack of acceptance by teachers and classmates. In Focus Group 1, VCCs stated that they are

#### Liya's request



Liya is a 5 year old girl with spina bifida. Although Liya's case is not severe she spends most of her time alone in the kitchen. Although the primary caregiver (her mother) wants to acquire a wheelchair for Liya, splints and a walker are more appropriate in order to help her learn to walk at this stage. Liya also needs basic physiotherapy to prevent possible contractures from forming, especially in the hip and knee joints. Apart from providing the mobility devices, starting intermittent catheterization and bowel management (toilet training) at her age is important to avoid other complications such as kidney damage and urinary tract infections. Unfortunately, Liya's mother and her VCC have no access to the necessary services or information.

connected with disabled clients who want to go to school, work, and/or participate in everyday life but could not because they do not know how to and have to deal with community stigma and mobility issues. They see others who are doing these things – like the simple task of feeding themselves or do economic work like herding cattle and want to do so as well. Many VCCs observed that the availability of livelihoods activities through access to hammer mills and gardens were ways persons and households with disabilities could be supported and empowered. Focus Group 2, also noted that persons with disabilities want to participate in activities and that they want to work. One VCC stated that they have a client with a disability who is the goalkeeper for football games. Another talked about a man with a disability that is able to care for his family and cultivate.

*It is very true; the disabled people want to work and to be involved. If they see someone doing something, they would crawl nearer so that they see what his happening.*

*Some of these disabled like trying and doing their best. One disabled woman I know, doesn't walk but she does everything, she cooks, washes clothes and only needs help to put the clothes on the line, she washes and sweeps. Her only problem is walking.*

In households where additional support has been provided; quality of life has slightly improved. Persons with disabilities are already undertaking some income generating activities, particularly through support from CBOs, FBOs, like World Vision and NGOs, like Zambian Federation of Disability Organizations (ZAFOD). One household with a person living with a disability received a dairy cow from World Vision; the family has benefited through the selling of milk to community members and thus increased income and household availability to services and materials. However, one woman had to learn how to use her donated sewing machine through the observation of others; she would benefit from additional training support on tailoring and design. Support to persons with disabilities requires more than just providing material inputs but support with the view of enabling them to reach self-sufficiency. Through targeted livelihood training, the needs and abilities of households with persons with disabilities can result in greater self-sufficiency and improvements in household quality of life.

The observations by the VCCs and the needs and desires of individuals living with disability is reflected in the UN Convention on the Rights of Persons with Disabilities, however prejudice, stigma and discrimination too often influence and reinforce the perceived limitations of and the availability of resources for persons with disabilities. Many times persons with disabilities and service providers have the knowledge and materials of inclusive, responsive and empowering activities but the limited social consciousness around the needs, abilities and desires of persons with disability has not allowed for genuine inclusion. Despite individual eagerness for inclusion and greater access to opportunities, existing personal, community and organizational perceptions of disability hinders full inclusion.



### *Access and the Story of Ruth*



Ruth, age 32, is paralyzed in both legs. She can use her upper body perfectly well. After her interview, Ruth was asked what she thought could be done to make life easier for her. Ruth did not have any suggestions. In fact, her house was built in her presence but the builder did not consider making it user-friendly, such as by building a ramp to the door to make the house more accessible for Ruth.

This bore hole is about ten metres away from Ruth's

house. Like the house, the borehole was drilled under the supervision of a local NGO, but considerations were not made to make it disability user-friendly. At Ruth's nothing is user friendly.



This toilet door is too small to access with her wheelchair. Even though Ruth was present at the time when all of this construction took place, making it wheelchair accessible was not part of the building plan. Just like the house and toilet, the door space to the kitchen is too small for the wheelchair to enter. Every time Ruth wants to access the kitchen or the toilet, she has to come off the wheelchair.

Including Ruth in the building process and taking into consideration her daily living needs at the onset could have a dramatic impact on Ruth's life and the life of her family.

## **Discussion**<sup>7</sup>

Disability impacts people on the personal, household and community level. In agreement with the existing literature, the study reinforces the notion that poverty and disability are self-reinforcing, doubly so when the household has a chronically ill or PLWHA. It was found that in all settings, but particularly in resource constrained settings, different disabilities have different

<sup>7</sup> This study did not address the issue of violence towards people with disabilities or access to sexual and reproductive health services due to concerns about stigma, confidentiality and responsive legal and medical services, to truly understand the relationship between disability and HIV/AIDS on the household, it is appropriate to understand accessibility issues on sexual, reproductive and HIV support services for persons with disabilities.

impact on household behaviors, perceptions and opportunities. Persons with disabilities and their primary caregivers respond differently to the stressors based on the perceived or real vulnerabilities and contributions to the household in both the short- and long-term.

Households in Chongwe are forced to respond to the competing needs of both disability and HIV and AIDS with limited financial and human resources and must balance the opportunity cost of productive labor with the need for medicine, transport and clinic costs. Food security and livelihood of households are influenced by the cumulative and reinforcing effects of chronic poverty, chronic illness, lack of educational opportunities, collapsed markets, and weakened institutional capacity which are difficult to disentangle from the HIV/AIDS pandemic in Zambia (Wieggers, Curry, Garbero, & Hourihan, 2006). Primary caregivers and households need to increase time and already limited resources to persons with disability and persons with HIV/AIDS, which are directed away from income generating activities that then keeps the households, communities and country in a cycle of poverty.

The cycle of household poverty impacted by disability and HIV/AIDS reveals few aspects of positive physical wellbeing. A person chronically ill because of HIV/AIDS and a person with a disability in the same household must share/compete for the primary caregivers' time and resources. As people with disabilities have less access to the things that can help them means that they are more dependent upon caregivers than other non-disabled family members which can compound the household's vulnerability. Their dependent status also makes a vulnerable household member who is disabled more vulnerable to neglect and/or abuse. In addition to the vulnerabilities faced by the person with the disability, primary caregivers are themselves becoming sick and depressed due to the multiple stressors.

Rural and peri-urban health care is provided by VCCs and Community Health Workers who have limited training and resources related to support for persons and households with disability. Oftentimes as this study found, as a result of this limited training, VCCs have stereotypical views of disability that can themselves add to the barriers faced by persons with disabilities that can exacerbate household vulnerability. It is necessary for those working on HIV/AIDS and other development assistance issues to acknowledge that disability exists and address it as a human rights issue, which if ignored, contributes to poverty and vulnerability. NGO/CBO/FBOs working in these rural areas need to put in place mechanisms for the inclusion of disability policies and trainings within their poverty reduction strategies with the goal for active participation of persons with disabilities or primary caregivers of disability affected households. Furthermore, these groups should take deliberate steps to mainstream youth with disabilities or primary caregivers of disability affected households into all livelihood activities like those reaching the non-disabled households.

The opportunity cost of time is limited for primary caregivers; without support systems, they must do all of the work to support the family member with a disability while balancing these activities with the need to leave them to participate in market activities or farming activities to bring money into the household. With the generalized AIDS epidemic in Zambia, support systems are already stretched to their breaking point, leaving little, if any, support for persons and families with disabilities.

The UN Convention affirms the paradigm shift from considering persons with disabilities as objects of charity, medical treatment and social protection to subject of human rights, able to make decision about life and the future on their own behalf (Disabilities, 2008), in Zambia the lack of access to basic services, the stigma and discrimination towards families and individual with disabilities and continuing cycle of poverty, makes the tenants of the UN Convention difficult to realize. Furthermore, Article 1 of the Convention states, that countries must “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disability, and to promote respect for their inherent dignity” (United Nations, 2006). Having ratified the Convention and as a country with explicit laws regarding disability, persons with disabilities in Zambia lack full access to the tenants prescribed in the Convention.

Lack of educational opportunities for person with disabilities in Chongwe and Zambia in rural, urban and peri-urban areas furthers limits long-term poverty reduction activities. The Zambian Poverty Reduction Strategy Paper targets providing infrastructure for disabled persons, however, lack of financial resources and political commitment have limited progress on increasing any infrastructure for persons with disabilities. Economic/productive activities for person with disabilities in the Zambian context, particularly in Chongwe is limited to agriculture and charcoal production and their related market activities. Charcoal production is seen as a possible activity for persons with disabilities because it requires limited mobility but this is not possible for those with respiratory issues. The opportunity for a person with a disability to maximize these activities can be limited by chronic illness and the cost and complexity of transport to markets. Providing appropriate education, empowerment and resources for persons with disabilities to meaningfully contribute to their households allows households and persons with disabilities to be their own agents of change.

Simple medical and social interventions and services have the potential to dramatically change access and inclusion of persons with disabilities in their community and reduce the strain on primary caregivers and household members. “Full and effective participation in society on an equal basis with others,” requires that persons with disabilities have access to medical interventions (as desired) as well as equal access to education, family, productive labor, and economic opportunities at the household, community, district, and national levels (United Nations, 2006).

If disability is ignored in development assistance, household vulnerability can be exacerbated, caregivers overwhelmed, and poverty deepened. As this research indicates, families and caregivers make choices regarding which family members receive assistance or have access to healthcare, education, and work opportunities. Poverty in households with disability and other chronic illnesses as a result of HIV/AIDS – and indeed other types of chronic illnesses as well are self-reinforcing for the individual and the collective household. Until full access and inclusion is achieved, disability and HIV/AIDS will continue to negatively impact each other. Persons with disabilities have the legal and moral right to fully participate in society.

## Recommendations

Jill Hanass-Hancock from the Health Economics and HIV/AIDS Research Division (HEARD) at the University of KwaZulu-Natal, affirms “there is a tremendous need for knowledge distribution on this topic, as advocates often need hard data to convince health officials of the need to act on disability issues” (Hanass-Hancock, 2009). This study highlights the need for further research to understand the complex nature of disability and HIV/AIDS’s impact on households in Chongwe, Zambia and around the world. The interrelated nature of poverty, illness and disability requires complex, inclusive and fully conceptualized policy and programs. Although the availability of ART is on the rise, with over one million Zambians living with HIV and AIDS and an estimated one million or more Zambians living with a disability, this is the time to ensure an inclusive and coordinated plan of action.

### **Opportunities for Further Research on Disability and HIV/AIDS**

- Large scale, randomized and rigorous assessment of HIV/AIDS and disability prevalence with professional public health experts, social scientists, anthropologists, and disability experts and advocates
- Understanding individual perceptions around disability as a result of HIV/AIDS and other illnesses versus disability from childhood
- Deeper exploration into the differences in care seeking behavior for persons with disabilities and for non-disabled persons
- Access to services and education for person with disabilities on sexual and reproductive health education and the related services
- Research to better understand why and how persons with disabilities seek assistance from traditional healers, research on the social and economic costs of providing such services and research on how traditional healers can provide more referrals into the formal medical and social service systems
- Research issues of resentment: households of non-disabled persons or non-HIV/AIDS affected and the issues of resentfulness regarding the assistance provided to those households with a disability
- Impact research on small grants for income generation; small holder farming, livestock, knitting
- Experiences, impact and needs of individuals disabled as a result of HIV/AIDS

Lack of resources should not be a justification for inaction, by the GRZ or by donors. Effective activities and interventions may just require good planning rather than considerable financial investments. It is the duty of a country’s government, particularly one that has ratified the Convention to meet the test of progressive obligation by providing at least the bare minimum of services and undertake actionable efforts of inclusion in the policy and program debate and in design. As a result of this study, VCCs, persons with disabilities, primary caregivers, World Vision Zambia, and RAPIDS staff have requested and started to receive expanded training and

support around inclusion of persons with disabilities in all program activities including in the adaption of existing programming.

Communities in rural areas maintain their own leadership and decision making systems through headmen councils or traditional leaders that have authority to influence certain community activities and behaviors. There is a need to recognize that through these established structures, disability sensitization and education is possible. Community representatives like the local government councilors, constituency development or resident development committees can include persons with disabilities. Participation of persons with disabilities in decision-making should be extended to various board services commissions to give equal opportunities and reduce need for mid- or post-construction project adjustment. If capacity is built among these leaders and committees, then they can effectively influence processes in line with the inclusion of persons with disabilities. Development assistance providers must also recognize that they do not understand the nuances of disability, and must seek out and establish partnerships with the leaders of disability rights organizations, disability professionals and disabled persons themselves to ensure that programs are appropriately designed and implemented. When NGOs and disabled persons organizations' partner in the planning and implementation processes there is a win-win situation where the former has capacity to implement and the latter provides the expertise needed to include specific disability approaches in development activities.

To ensure persons with disabilities, whether HIV+ or HIV- are fully included in anti-poverty and HIV prevention, care and support initiatives, the Yale University Center for Interdisciplinary Research on AIDS proposes a General Framework for Inclusion of Disabled People in HIV/AIDS Outreach Efforts. Strategies for the inclusion of disabled person's organizations are conceptualized as a continuum from Type I to Type III (Groce, Trasi, & Yousafzai, 2006):

Type I: Inclusion as Part of General HIV/AIDS Outreach with No Special Adaptations

Type II: Minor Adaptations to General Programs that Foster Inclusion

Type III: Disability Specific Programming

In order to achieve the MDGs, and fulfill the promises of the UN Convention, organizations, projects, donors, and government services should not just help the caregiver or provide additional external services like nursing, but enable persons with disabilities to be more self-sufficient. This would aid the primary caregiver, the family and empower the person with the disability. In order to mainstream persons with disabilities with meaningful opportunities, we recommend, in no particular order:

- 1) More services for persons with disabilities that empower them through independence and self-sufficiency;
- 2) Environmental adaptation in building and service design for daily use including accessible buildings, appropriate water and sanitation sites and reasonable accommodation for education and work;

- 3) More support to primary caregivers so that they have the self efficacy and problem solving tools to develop household level mechanisms for determining their needs and opportunities;
- 4) Community health workers and volunteers need more training on disability and awareness in order to bring information to persons with disabilities, primary care givers and families;
- 5) Alliance between service providers and disabilities groups like ZAFOD to share insight and expertise with the care community; and
- 6) Additional resources for research around household vulnerability, disability and HIV/AIDS in order to drive effective inclusive policy and programming, including DHS data collection on disability.

All these activities are in alignment with the UN Convention and move Zambia towards achieving the MDGs and EFA. Development professionals working on HIV/AIDS and other issues must acknowledge that disability exists and address it as a human rights issue which if ignored, contributes to poverty and vulnerability. Until persons with disability are fully included in Zambia and not treated as a charity case, Zambia will not be utilizing its whole population in its work to reduce and eliminate poverty.

For additional information on methodology and study tools, please contact Kathryn Fleming at the American Institutes for Research at [kfleming@air.org](mailto:kfleming@air.org).

## References

- Central Statistic Office. (2003). *Summary Report for the 2000 Census of Population and Housing*. Lusaka: Desktop Publishing Unit, CSO.
- Central Statistical Office. (2000). *2000 Main Zambia Census Report*. Lusaka: Government of the Republic of Zambia.
- Demographic and Health Survey. (2009). *Zambia Demographic and Health Survey 2007*. *Central Statistical Office (CSO), Ministry of Health, Tropical Diseases Research Center, University of Zambia, and Macro International Inc*. Calverton, Maryland, USA: CSO and Macro International Inc.
- Disabilities, U. N. (2008). *Presentation: Convention on the Rights of Persons with Disabilities and its Optional Protocol*. Geneva: United Nations.
- Education for All. (2008). *Global Monitoring Report*. Paris: UNESCO.
- Elwan, A. (1999). *Poverty and disability: a survey of the literature*. Washington, DC: World Bank.
- Government of the Republic of Zambia. (2002, March). *Zambia Poverty Reduction Strategy Paper*. Retrieved November 2, 2009, from International Monetary Fund: [www.imf.org/external/np/prsp/2002/zmb/01/index.htm](http://www.imf.org/external/np/prsp/2002/zmb/01/index.htm)
- Groce, N. E. (2006). *Guidelines for Inclusion of Individuals with Disability in HIV/AIDS Outreach Efforts*. New Haven : Yale University Center for Interdisciplinary Research on AIDS.
- Groce, N. E. (2005). HIV/AIDS and Disability. *Health and Human Rights* , 8 (2), 215-225.
- Groce, N., Trasi, R., & Yousafzai, A. K. (2006). *Guidelines for Inclusion of Individuals with Disabilities in HIV/AIDS Outreach Efforts*. New Haven, Connecticut: Yale University.
- Hanass-Hancock, J. (2009). Disability and HIV/AIDS - a systematic review of literature on Africa. *Journal of the International AIDS Society* , 12, 34-44.
- Hayes, A. (2007, September 30). *General Information on Disability and Development*. Retrieved November 14, 2009, from USAID: Women in Development : [http://www.usaid.gov/our\\_work/cross-cutting\\_programs/wid/pubs/DisabilityInformation\\_Sept2007\\_1.pdf](http://www.usaid.gov/our_work/cross-cutting_programs/wid/pubs/DisabilityInformation_Sept2007_1.pdf)
- ICLEI. (2008). *Chongwe, Zambia: A Case Study Report on Capacity Building for Integrated Governance in the Management of Water and Sanitation*. Local Governments for Sustainability: Water Campaign.
- Loeb, M. E., Eide, A. H., & Mont, D. (2008). Approaching the measurement of disability prevalence: The case of Zambia. *European Journal of Disability Research* , 2, 32-43.
- Mont, D. (2007). *Measuring Disability Prevalence*. Washington, DC: World Bank - Disability and Development Team.

Shakespeare, T., & Watson, N. (1997). Defending the Social Model. *Disability and Society*, 12 (2), 293-300.

South African National AIDS Council. (2008). *HIV, AIDS and Disability in South Africa*. South Africa.

UNAIDS. (2009). *Disability and HIV Policy Brief*. Geneva.

UNAIDS. (2008). *Epidemiological Fact Sheet on HIV and AIDS*. Geneva: UNAIDS.

UNESCO. (2008). *Mainstreaming Disability in the Development Agenda*. Geneva: United Nations Economic and Social Council.

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Washington, DC.

Wiegers, E., Curry, J., Garbero, A., & Hourihan, J. (2006). Patterns of Vulnerability to AIDS Impacts in Zambia Households. *Development and Climate Change*, 37 (5), 1073-1092.

Yousafzai, A., & Edwards, K. (2004). Double Burden: A situational analysis of HIV/AIDS and young people with disabilities in Rwanda and Uganda. London: Save the Children .

Yousafzai, A., Dlamini, P., Groce, N., & Wirz, S. (2004). Knowledge, personal risk and experiences of HIV/AIDS among people with disabilities in Swaziland. *International Journal of Rehabilitation Research*, 27, 247-251.





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