



SOUTHERN AFRICAN INSTITUTE
for POLICY AND RESEARCH

Occasional Papers Series

Assessing Civil Society Involvement with Persons with Disabilities in
the Realm of Health Education and Health Service Delivery

Jessica Iyer and Laura Museau

19 August 2014

SAIPAR #2014/3

Abstract

The World Health Organisation estimates that out of the 13.2 million people in Zambia, two million people have a disability (International Labour Organisation, 2013). Lack of resources coupled with stigmatisation has led to the isolation and vulnerability of this group. The UN Convention on the Rights of Persons with Disabilities was held in 2006 to not only define disability, but to also outline the rights of the disabled. In response, Zambia passed the Persons with Disabilities Act No. 6 of 2012. The new act shifted from welfare to a human rights focus, promoting equal opportunities and community integration for persons with disabilities (PWD; National Implementation Plan/National Disability Mainstreaming Plan, 2013). Civil Society Organisations (CSOs), in particular, Disabled Persons Organisations (DPOs), work on a ground level to promote the rights and services outlined in the act, and fill in gaps where the government cannot provide.

This research sought to identify how well CSOs in Zambia are filling the gaps in health education and service delivery amongst PWD. Research was conducted through semi-structured interviews with various CSOs and DPOs in Lusaka, Zambia, and through a review of existing literature. Results demonstrated that the DPOs encountered problems with communication and solidarity, funding, and lack of capacity. As a result, the DPOs were significantly lacking in their involvement in health education. Although all the organisations provided delivery of services in some capacity, most of their programmes were tailored towards advocating for basic rights, and not necessarily those rights in relation to health.

Abbreviations

AHDI	Archie Hinchcliffe Disability Intervention
AIDS	Acquired Immunodeficiency Virus
CSO	Civil Society Organisations
DPO	Disabled Persons Organisations
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
JCTR	The Jesuit Centre for Theological Reflection
MDG	Millennium Development Goal
NAC	National AIDS Council
PPAZ	Planned Parenthood Association of Zambia
PWD	Persons with Disabilities
TEVET	Technical Education, Vocational and Entrepreneurship Training
UNDP	United Nations Development Program in Zambia
WHO	World Health Organisation
ZAFOD	The Zambia Federation of Disability Organizations
ZAMDHARP	Zambia Disability HIV human rights program
ZAPCD	Zambian Association of Parents for Children with Disabilities
ZAPD	Zambia Agency for Persons with Disabilities
ZGF	Zambian Governance Foundation
ZHDR	Zambia Human Development Report
ZISSP	Zambian Integrated Systems Strengthening Program
ZNAHI	Zambia National Association of the Hearing Impaired
ZNAPS	Zambian National Association for the Partially Sighted

Introduction

Like many developing countries, Zambia has a limited capacity to address the issues of the disabled population. In response, Zambia's policy approach has been to mainstream disability. Disability Mainstreaming is a process that ends exclusion by ensuring that PWD can enjoy the same human rights and benefits as able-bodied persons (Zambian Governance Foundation, 2013). Despite having a comprehensive framework for dealing with disability, the government's current involvement in its implementation is limited. CSOs have stepped in to advocate for the rights of disabled persons' and to implement policies pertaining to their needs. Given the importance of CSOs in advocating for PWDs, how well are CSOs able to fill the gap and ensure equal health service delivery and health education for PWD? This paper argues that CSOs are limited in their ability because they lack funding, capacity, and solidarity amongst themselves.

Civil Society "encompasses all organisations and associations that exist outside the state and market" (Ghaus-Pasha, 2004). In Zambia, these organisations consist of "professional bodies, trade unions, gender based groups, human rights and advocacy groups, service-oriented CSOs, faith-based organisations, international NGOs and the media" (Civil Society Profile: Zambia, 2011). In its broadest sense, the role of the civil society is to promote good governance by improving the government's transparency, effectiveness, openness, responsiveness, and accountability (Ghaus-Pasha, 2004). They achieve this by monitoring state performance as well as the actions of political officials and also by mobilising vulnerable communities to increase their participation in political affairs (Ghaus-Pasha, 2004).

Of the countries profiled in the Civil Society Profile, Zambia shows to have one of the highest levels of participation (Civil Society Profile: Zambia, 2011). Although civil society participation is an important driving force behind economic, social, and cultural advancement in Zambia, of the many CSOs that exist, only about 50% of them have a stable financial platform (Civil Society Profile: Zambia, 2011). Additionally, many experience high

staff turnover as members shift to international NGOs, causing them to be highly dependent on volunteers (Civil Society Profile: Zambia, 2011). As a result, it is common for emphasis to be placed on issues that are more pressing, such as HIV/AIDs, thus leaving issues such as disability untouched. While the ratification of the Persons with Disabilities Act No. 6 of 2012 raised attention to the mainstreaming of disability within the health sector, very few interventions and programmes actually exist.

This paper is organised as follows. We will first provide background on the current state of disability in Zambia, including the multifaceted aspects of disability that makes it a hard issue to tackle, followed by the legal framework for dealing with disability. This section will be followed by a methodology on how we evaluated CSOs' effectiveness in health education and health service delivery for PWDs. We conclude by presenting our findings on CSOs, outlining the strengths and limitations. We will also explain the impact this has for disabled persons in Zambia, and close by touching on possible areas of improvement.

Background

There has been controversy in the field as to what constitutes disability. The International Disability Movement defines disability as the disadvantages stemming from the “limitations imposed on them by attitudinal, social, cultural, economic, and environmental barriers to their participation in society”. Instead of focusing on their impairments from a medical standpoint, this definition argues that it is the exclusion and discrimination that PWDs face that is disabling (Albert, 2004). The disabled are among the poorest not because of their impairment, but because they lack authority to advocate for themselves (Albert, 2004). Shifting the focus to social transformation opens the door for access to proper health, education, and employment, thus granting them a voice and power to advance themselves. Although Zambia has been moving towards mainstreaming disability, PWD still lack proper access to education, health-care, and employment. While it is estimated that about 15% of the Zambian population is disabled (WHO, 2011), PWD continue to be one of the most marginalised groups in Zambia (Banda-chalwe et al, 2012). A large part of this marginalisation stems from the lack of appropriate resources that cater to their disabilities. For example, organisations, health facilities, and schools often fail to adopt the necessary instruments that would make these establishments disabled-people friendly (Banda-chalwe et al, 2012). Additionally, high level of stigmatisation stemming from the notion that most disabilities are the result of witchcraft or other non-biological social misfortunes discourages PWD from seeking out resources offered by their communities (Banda-chalwe et al, 2012).¹

Perceptions of Disabled Persons in Zambia

In Zambia disability is seen as a consequence of social-cultural and religious misfortunes of the family or individual (Mung’omba, 2008; Eide & Loeb, 2006; Smith et al, 2004). Research from a master’s thesis written by Mutoloki (2012) on disability in Zambia found that the

¹ Witchcraft itself is not so much a belief system, as it is a term associated with inexplicable phenomena to explain cases of misfortune- life threatening misfortune- death, diseases, and accidents. See, Scott D. Taylor, *Culture and Custom of Zambia*.

type and form of stigma varied between communities and families. From focus groups throughout Livingstone and Kazungula Districts, Mutoloki found that it was generally thought that having a disabled child brought shame to the family. When hosting visitors, families shared that they would hide their disabled child so that others did not have to be “be exposed” to them. Mutoloki states, “disability was regarded as some form of contagious disease that the rest of the community was afraid to come in contact with” (Mutoloki, 2012). It is important to consider that these views are not consistent throughout all of Zambia, but this study illustrates that in some communities PWD are not considered equals.

This discrimination prompted Disabled People’s Organisations (DPOs) to convene with government leaders, employers and other stakeholders in Lusaka, Zambia, in 2010. This convention, supported by the International Labour Organisation (ILO), highlighted discrimination that PWD face from the government and society, and emphasised their desire to be mainstreamed and to participate in life-choices (Banda-Chalwe). Two years later, Zambia revised existing legislation and passed into law the Persons with Disabilities Act No. 6 of 2012, which takes a more human rights approach to disabilities, with hopes to better integrate PWD into society as equals.

Poverty and Employment

According to researchers Trani and Loeb (2010), unemployment rates in Zambia are high, with disabled persons being largely over-represented in this unemployed category. They noted that the issue stems from stigma and people’s misconceptions that PWDs are unable to work due to their impairments. However, persons who are not victims of stigma find it hard to gain employment because they lack the skills. Hamusunga (2012) explains how the Technical Education, Vocational and Entrepreneurship Training (TEVET) system does not effectively aid them in gaining skills. The TEVET system runs under an act that states “special needs of people with disabilities will be taken into consideration” (International Labour Organisation, 2013). However, Hamusunga (2012) claims that these TEVET training institutions are not teaching their pupils skills that will aid them in the current job

market or towards self-employment. Even with this system that includes PWD, many students are graduating and are finding it difficult to find employment.

Lack of employment amongst PWD constitutes the difficulty in alleviating poverty. Zambia is one of the many nations striving to accomplish the Millennium Development Goals (MDGs) by 2015, with the objective to eradicate extreme poverty and hunger from the world. As of the 2013 MDG report, extreme poverty has been halved worldwide; however, sub-Saharan Africa only experienced an 8% decrease in poverty between 1990 to 2010. Although disability is not mentioned explicitly in the MDGs, disability and poverty are intrinsically linked (Thomas, 2005). Persons with disabilities find it difficult to secure employment that accommodates their handicap. Without proper employment, maintaining stable economy is challenging, especially in terms of affording proper health services (Mitra, Posarac, & Vick, 2011). As a result, the conditions that accompany the disability may exacerbate, or new ones may form should the root of the disability spread, thus cycling back to the inability to establish employment.

Education

In addition to the lack of employment, disabled children find it difficult to access proper education. Globally, after realising that education is key to national development and individual well-being, the first major Education for All (EFA) conference was held to address this human rights issue (UNESCO, 1990). Within this conference the exclusion of vulnerable and marginalised groups from education systems worldwide was brought to attention. To date, the most current form of legislation worldwide to address inclusive education as a fundamental right is the UN Convention on the rights of persons with disabilities of 2006. Although Zambia has ratified this convention into their legislation with the Persons with Disabilities Act (2012), the country remains challenged in obligating or supporting inclusive education. As of the 2011 Zambia Human Development Report (ZHDR), Zambia spends about 2-2.5% of its GDP on education compared to the 5% that of countries like Kenya, Malawi, and Uganda. Therefore, when faced with the costs of education, especially materials needed to accommodate disabled children, inclusive education comes with a very high price.

A study conducted by Susie Miles (2009) assessed the extent to which teachers were capable of engaging in inclusive education. For the purpose of her study, inclusive education was defined as the “process of increasing the presence, participation and achievement of all students in their local schools with particular reference to those groups of learners who are at risk of exclusion, marginalisation or under-achievement” (Miles et al., 2003, 9). Miles (2009) discovered that many teachers were wary of partaking in inclusive education because they regarded it as a “special needs” issue that deserved to be handled by trained specialists. As a result, many of the teachers declined taking part in the study, neglecting the fact that they already had the creativity and skills needed to adopt a way of demolishing some of the many existing barriers to inclusive education. For example, one teacher reported that after overcoming her fears, she was able to touch, communicate, and interact with a child diagnosed with albinism in a way that made her pupils more open to engaging the child as well. The teacher reported that by the end of the class day she was able to notify the areas of weakness in the child, including his poor eye-sight, and take the recommended action. Nevertheless, without some form of intervention on behalf of the teachers, it is unrealistic for the government to expect teachers to be able to enact legislation without proper information or even knowledge on disabilities to eliminate all the myths (Miles, 2009).

Health Education

Health education is vital in improving the health and longevity of a population. Zambia is currently facing an HIV epidemic, with a national prevalence rate of 15% (Nixon et al, 2014), leaving many affected by this disease in some capacity. In particular, the HIV/AIDS situation among the disabled is complex and disconcerting. Due to limited and conflicting information, the definition of disability, and quality of data in Zambia, it has been difficult to determine the HIV prevalence rate among the disabled. However, there is an emerging body of literature on the increased HIV vulnerability among the disabled due to the historic exclusion from HIV planning and programming, lack of education, sexual abuse, and precarious access to healthcare. The disabled were historically excluded from HIV programmes due to erroneous belief that PWD were not sexually active and therefore not at risk of HIV infection (Nixon et al, 2014).

The onset of HIV/AIDS and increasing urbanisation in Zambia has altered the traditional methods of health education, more specifically sexual education, among the youth. Traditionally, boys and girls received sex education primarily from their grandparents. However, with urbanisation, distance between families has hindered this practice. As a result, sexual education was integrated into school curriculums from grade five onwards to secondary schools in the 1990s. Methods of both contraction and prevention are taught, including condom use, treatment options, and abstinence discussions. Sexual education in schools now provide clearer sexual information, despite lasting myths that still remain in both urban and rural areas of Zambia (Rasing, 2003).

Despite the integration of sexual education into schools, many children with disabilities will not receive this education due to their absence in many school systems. In fact, children with disabilities account for one third of the 72 million children out of school worldwide (UNAIDS, 2009). With disabled children out of school, they are excluded from the HIV/AIDS, sexual, and reproductive education provided in these settings, leaving them more vulnerable to risky behaviors and poor health.

Health Service Delivery

Without access to timely and quality health service, people fall into a cycle of disease and ill health, leading to low productivity, low income, and low quality of life. Shortage of healthcare professionals, low availability of drugs at health centers and hospitals, and distance to health care facilities continue to delay improvement of health issues in Zambia (Zambia Human Development Report, 2011). Each of these factors varies across provinces, with a worse situation among the rural provinces (Eastern, Laupula, Northern, Western, and North Western). The number of healthcare facilities has increased over the years; however, people still face challenges related to geographical coverage and distance from rural areas (Zambian Human Development Report, 2011).

Given the challenges faced by the general population for service delivery, the disadvantages for PWD both escalate these challenges and pose new ones. For example, a qualitative 2014 study on HIV health services for the disabled found three major barriers while seeking

treatment; disability related discrimination; communication barriers and concerns of confidentiality; and movement and mobility challenges. In terms of communication challenges, one deaf participant expressed, “I don’t access any information. There is no one to interpret, so it means that it is not disability friendly...I wish there was interpreters in these hospitals” (Nixon et al, 2014, 5).

In 2003, researchers conducted a qualitative study in Lusaka where they interviewed 24 women with disabilities (specifically those with neuromusculoskeletal and movement related disabilities) and 25 safe motherhood/reproductive public sector health service providers. This study expressed the major barriers that disabled women face when accessing maternity care. These barriers include physical access to facilities, the need for reproductive health care, and stigmatisation faced. In Zambian culture there is a strong importance in having children. Resultantly, many disabled women in the study explained that they would allow themselves to be exploited for fear of not receiving another opportunity for sexual affection. This fact underscores the need for family planning and other reproductive health services among these women.

Furthermore, although the general attitude voiced by health workers was one of acceptance and inclusion, disabled patients reported otherwise. Disabled women felt like they attracted a lot of negative attention when using maternal services, stemming from misconceptions and curiosity surrounding their pregnancies. One disabled interviewee stated, “When they see you they laugh...seeing your disability and the pregnancy on the other hand” (Smith et al, 2004, 124). A staff member described the reactions of other service users as, “they get surprised by a disabled woman getting pregnant and they ask her a lot of questions” (Smith et al, 2004, 124). These reactions may have had harmless intentions, but they reinforce isolation and exclusion among service seeking disabled women (Smith et al, 2004).

Legal Framework for Disability in Zambia

In December of 2006, the UN Convention on the Rights of Persons with Disabilities convened and drafted numerous articles describing the equal freedoms that PWD should

enjoy. In 2012, Zambia domesticated this convention into their personal legislation and passed into law the Persons with Disabilities Act No. 6. Under this Act, as well as the UN Convention, it is stated that PWD should be able to enjoy equal human rights as well as be treated equally to able-bodied persons. The 2006 UN Convention recommended that a committee on the rights of persons with disabilities be established to carry out the functions listed in the convention (UN Convention). To comply with the convention, the Zambian government created the Zambia Agency for Persons with Disabilities (ZAPD). Through this governmental agency, it is expected that the civil society can gain the resources and aid they need to help them carry out their work. This legislation exists on a policy level, and to date it has been difficult to achieve this equality on the ground level.

The International Labour Organisation (ILO) has noted that in order for persons with disabilities to be included in society there needs to be improvement within basic education, vocational training relevant to the job market, and jobs suited to their skills and interests (International Labour Organisation, 2013). The ILO has a project entitled “Promoting Rights and Opportunities for People with Disabilities in Employment through Legislation”, which aims to improve the capacity of the government by address discrimination and rights violations amongst persons with disabilities in employment, while also granting disabled persons access to skills development (International Labour Organisation, 2013).

Research Methodology

A review of relevant literature was done along with semi-structured interviews with a diverse set of stakeholders in Lusaka. These stakeholders included specific DPOs, other relevant CSOs in Zambia's health sector, and governmental organisations. Stakeholders were contacted through collaboration with the South African Institute of Policy and Research (SAIPAR) and the Zambian Governance Foundation (ZGF). Thirteen interviews were conducted, and included representatives from the agency Zambian Agency for Persons with Disabilities (ZAPD), a disabled umbrella organisation called the Zambia Federation of Disability Organisations (ZAFOD), Archie Hinchcliffe Disability Intervention (AHDI) at University Teaching Hospital, and the National AIDS Council (NAC), amongst other organisations. We posed questions ranging from what projects they were currently involved in to how they went about building capacity and receiving funding. This field research was conducted in Lusaka, Zambia throughout June and July of 2014.

Preliminary Research Findings

Interviews with various stakeholders dealing with PWD shed light on the current state and progress of these organisations. After compiling the data from these interviews with the selected CSOs in Lusaka, Zambia for two months, we have found a gap in health education and a small involvement in health service delivery specific to disabled persons among CSOs. We have identified three barriers to CSO involvement in these areas, as well as their strength in advocacy.

Communication and Collaboration

Almost every organisation met with commented on the need for communication improvement amongst DPOs. The National Aids Council (NAC) and ZAPD both serve as quasi-governmental organisations, designated to be a linkage between the government and CSOs. Despite this, some organisations have expressed that ZAPD is not providing much support outside of registering DPOs. DPOs need to work through these organisations to have their voices heard at a governmental level. However, a representative from the NAC explained how there is a “we and them” mindset between DPOs and donors, explaining that unless summoned DPOs scarcely reach out to them for non-funding related issues. DPOs push to be more supported, while the NAC wants them to improve their self-advocacy (Personal Communication, July 2014).

In Zimbabwe, a case study was done examining the role that civil society played in the disabled population. It was reported that the reason behind the failure of past efforts was the lack of cohesion among DPOs. “They attributed failure of past efforts at securing policy change largely to the lack of organisation on the part of disabled persons as they pressed for diverse and at times contradictory policy changes through various organisations that catered for divergent disabilities” (Ghaus-Pasha, 2004). In response to this realisation, the DPOs combined their labor, skills, and resources to form one organisation with a common voice, Zimbabwe Federation of the Disabled (ZIFOD). With the government only having to deal with one entity, they were better able to build a trusting and transparent relationship that enabled the formation of the Disabled Personalities Act (1992). However, it was

through this established relationship that ZIFOD was able to sensitise the government on their necessities and challenges and have the government listen. The result was that the act effectively met the needs of disabled persons by making more public buildings accessible, providing equal employment opportunities, and access to schools of their choice (Ghaus-Pasha, 2004).

Funding

Funding was possibly the largest barrier that each organisation met with faced. DPOs lack the funding to carry out their desired projects and build on their sustainability as organisations. On the other hand, funders lack the capacity to support each and every DPO. Both funders and DPOs are conflicted. DPOs feel as though they are underrepresented and do not receive enough support in the process of writing grants to receive funding. However, funders cannot support these organisations unless grants are submitted. A representative from ZAPD expressed how the unpopular nature of disability as a topic among the government and donors is what caused underfunding in the past. As a result, DPOs struggle to receive funding which limits their ability to carry out desired projects. Additionally, donors are hesitant to choose to support certain DPOs over others on the issue of being discriminatory in their choice. For example, a representative from the United Nations explained that giving funds to an organisation catered solely to the blind could cause inaccurate media criticism, accusing the UN to be partial.

As a result, the United Nations Development Plan (UNDP) expressed that they fund the Jesuit Center for Theological Reflection (JCTR). This organisation is not disability specific, but they advocate for economic and social rights among poor and vulnerable groups. This group is in the process of making themselves more available and well versed in disability issues, with hopes to better support DPOs. For example, they are striving to ensure that 10% of their programme participants are PWD and hope to publish some of their relevant research in braille (Personal Communication, July 2014).

Lack of Capacity

Linked to financial insecurity is the challenge of building capacity among DPOs. To clarify, in this paper we are defining capacity as the comprehensive capability of an organisation to

carry out its goals. Some organisations are working towards building individual capacity; however, this can be seen as difficult without a consistent source of funding. This issue contributes to an intrinsic cycle: DPOs need funding to build capacity, but donors often times require a sustainable system before supplying. ZAFOD expressed in an interview that this is a major concern for development, since DPOs often do not have the resources or capacity level that donors want to see before funding. To combat this, ZAFOD holds regular meetings and workshops on capacity building, in which their DPO affiliates regularly attend. However, regular communication and status updates are lacking, which makes it difficult for ZAFOD to be a sustainable source of capacity building. Ultimately this leaves DPOs right where they started from, without capacity or a source of funding to improve (Personal Communication, July 2014). In attempts to improve, ZAFOD and their affiliates (CBM and the European Union) have supported the development of the National Implementation/National Disability Mainstreaming Plan. This plan is currently in the governmental review process for the adoption and implementation into the Persons with Disabilities Act No.6 of 2012 (Personal Communication, July 2014).

The former Community Based Intervention Association (CBIA), now known as the Archie Hinchcliffe Disability Intervention (AHDI) is one DPO focusing on both service delivery and health education among children with Cerebral Palsy. AHDI was first formed in 1993 by the then British High Commissioner's wife. When she left Zambia, she left the organisation under the supervision of another organisation called the Action on Disability and Development (ADD). Under this supervision, ADD provided both funding and capacity building. When the two organisations split in 2007, AHDI had been established into a sustainable body. Even though funding is a present challenge for AHDI, due to their well-established foundation, they are able to better carry out their services (Personal Communication, July 2014).

Today, AHDI has six community outreach centers throughout Lusaka. They provide physiotherapy rehabilitation services for disabled children as well as training workshops in physiotherapy management for parents and caretakers. Service is provided by trained volunteers, Special Education Needs Teachers, and physiotherapists. Along with health

service delivery, ADHI also proved to be one of the few organisations interviewed that provided health education to its participants. They currently conduct a Home School Based Education Programme, focusing on areas of development including: cognitive, self-help, language, socialisation, motor, and infant stimulation. Volunteers and special needs teachers then visit the child's home once a week, attending to their needs and educating the family (Personal Communication, July 2014). The history of this organisation provides an example of the importance behind both donor funding and capacity building.

Advocacy

The most popular focus among the organisations interviewed was advocacy. The Zambia Federation of Disability Organisations (ZAFOD), an umbrella organisation to twelve DPOs in Zambia, has services that include grant monitoring and knowledge dissemination on capacity building and human rights. One of ZAFOD's advocacy projects is the Zambia Inclusive Education Programme (ZIEP). By strengthening participation and the capacity for self-advocacy among communities, ZAFOD hopes to create linkages between these communities, the government, and service providers to deliver inclusive education for children with disabilities. ZAFOD also advocates for inclusive access to safe and clean water for PWD by partnering with the Urban Wash Project (Personal Communication, July 2014).

The Zambia Association of Parents for Children with Disabilities (ZAPCD) was formed in 2001 by parent groups aiming to help their disabled children claim their rights. Today, ZAPCD empowers children with disabilities to be self-advocates and builds capacity among parents so that they can be at the forefront of this advocacy. Along with ZAPCD, the Zambia Disability HIV Human Rights (ZAMDHARP) programme advocates for the mainstreaming of PWD in issues surrounding HIV, health, and human rights (Personal Communication, July 2014).

After analysis of stakeholder interviews, we gathered that advocacy is an area that does not require a consistent source of funding. As a result, this is an area that DPOs feel they can accomplish most without relying on capital.

Discussion

Despite the recent advancements made in recognising the disabled as a key vulnerable population, much still remains to be addressed. Today, infrastructure of Zambia lacks the amenities necessary to accommodate the many disabled persons in its population. Though it was found that the civil sector is mostly responsible for accomplishing the needs of the people, civil society is lacking the capacity to meet the needs of PWD. This leads to the ultimate question, without building capacity among themselves, how can DPOs build capacity amongst the disabled population?

After interviewing the DPOs and listening to their challenges as well as achievements, the lack of capacity will continue to limit the amount of work that they can complete. Although they have listed funding as the major contributor to their lack of capacity, communication barriers within the DPOs need to be improved before donors will invest in their projects. Issues of discrimination can arise when donors invest in one organisation catered to a specific disability while ignoring the other disabilities. Similarly, even among the same disability, more than one organisation exists making it hard to decide to whom to allocate funding. ZAPD was created in part to improve solidarity among DPOs, yet they also lack financial and technical resources to execute their goals and assist in the goals of other DPOs.

Though the situation in Zimbabwe is not perfect, they still have been able to make strides in mobilising their limited resources to improve the lives of the disabled. Many of the Zambian DPOs overlook the option of joining more collectively because of their differing objectives. However, if they then don't improve their communication, and collaboration with ZAFOD and ZAPD, then resources will continue to be scarce and improvement minimal. ZAFOD explained that they were waiting for the passing of the National Disability and Mainstreaming Plan to take a more aggressive approach in tackling disabled persons issues. However, once the legislation is passed, the DPOs will still need the capacity to implement the policy on a ground level.

In sum, we investigated what civil society organisations are doing in service delivery and health education for disabled persons. Although our research was constrained to only two months, we found that much improvement is needed on a basic level amongst the DPOs. With the exception of AHDI, none of the other DPOs had the necessary resources to provide health education. DPOs are currently most involved advocating for the rights of disabled persons, but even in this regard, they are struggling to be heard. Before health service delivery and health education can be addressed, improvement has to be seen amongst the DPOs themselves. Without proper communication and collaboration amongst these DPOs, Zambia's objective to mainstream disability will be difficult to obtain, and as a result, disabled persons will continue to lack access to proper health services and education.

References

- Aisha, Ghaus-Pasha. 2004. "Role of civil society organizations in governance."
- Bill, Albert. 2004. "The social model of disability, human rights and development." Retrieved from www.disabilitykar.net/pdfs/social_model_briefing.pdf
- Eide, A. H., and M. E. Loeb. 2006. Living conditions among people with activity limitations in Zambia. A national representative study. SINTEF report, 1–189. Oslo: Norwegian Federation of Organisations of Disabled People.
- Government of the Republic of Zambia. 2012. "The Persons with Disabilities Act, No.6 of 2012." Lusaka, Zambia.
- Hamusunga, George. 2012. "An analysis of the performance of the Zambian education system." *Zambia National Education Coalition*.
- International Labour Organization (ILO). 2013. "Inclusion of People with Disabilities in Zambia. Factsheet."
- Jean-Francois, Trani and Mitchell Loeb. 2010. "Poverty and disability: A vicious cycle? Evidence from Afghanistan and Zambia." *Journal of International Development*. 24, S19-S52.
- Martha Banda-Chalwe, Jennifer C. Nitz, and Desleigh de Jonge. 2012. "Globalising accessibility: drawing on the experiences of the developed countries to enable the participation of disabled people in Zambia." *Disability & Society* 27, no. 7:917-34.
- Mitchell Loeb, Arne H. Eide , Jennifer Jelsma , Mzolisi ka Toni and Soraya Maart. 2008. "Poverty and disability in Eastern and Western Cape Provinces, South Africa." *Disability & Society* 23, no. 4, 311-321

- Mung'omba, J. 2008. Comparative policy brief: Status of intellectual disabilities in the Republic of Zambia. *Journal of Policy and Practice in Intellectual Disabilities* 5, no. 2:142–4.
- Mutoloki Emmah. 2012. “A Study of Socio-Cultural Barriers and Human Rights of Women with Disabilities in Livingstone and Kazungula Districts of Zambia.” Noragric Master Thesis. Norwegian University of Life Sciences.
- Nixon S. A., et al. 2014. “Perceptions of HIV-related health services in Zambia for people with disabilities who are HIV-positive.” *Journal of the International AIDS Society* 17:18806
- Philippa, Thomas. 2005. “Disability, poverty and the Millennium Development Goals: relevance, challenges and opportunities for DFID.”
- Rasing, Thera. 2003. “HIV/AIDS and sex education among the youth in Zambia: Towards behavioural change.” Retrieved from <http://asc.leidenuniv.nl/pdf/paper09102003.pdf>
- Sophie Mitra, Aleksandra Posarac, and Brandon Vick. 2011. “Disability and poverty in developing countries: A snapshot from the world health survey.” World Bank.
- Smith, E., S. Murray, A. Yousafzai, and L. Kasonka. 2004. Barriers to accessing safe motherhood and reproductive health services: The situation of women with disabilities in Lusaka, Zambia. *Disability & Rehabilitation* 26, no. 2: 121–7.
- Susie, Miles. 2009. “Engaging with teachers’ knowledge: promoting inclusion in Zambian schools” *Disability & Society* 24, no. 5, 611-24.
- United Nations. 2013. *The Millennium Development Goals Report*. New York: United Nations.
- UNAIDS, WHO, and OHCHR. 2009. Disability and HIV Policy Brief. Geneva: UNAIDS.
- United Nations Development Programme. “Zambia Human Development Report 2011: Service Delivery for Sustainable Human Development.” Lusaka, Zambia: UNDP.
- World Health Organization. 2011. Retrieved from <http://www.who.int/countries/zmb/en/>

Zambian Governance Foundation for Civil Society. 2013. "Disability mainstreaming toolkit for civil society organisations in Zambia." Lusaka, Zambia: ZGF.