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Removing Barriers Towards Inclusion: Sensitization and
Mainstreaming Intellectual Disabilities Issues at a
Community and National Level in Zambia

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Abstract

Persons with intellectual disabilities (PWID) are among the most marginalized groups in the world, experiencing social exclusion at higher rates than those without disabilities (Inclusion International, 2006). In Zambia, negative community attitudes cause stigmatization and discrimination of PWID, preventing access to community opportunities like education, employment, and social inclusion. At a national level, disability issues are not properly mainstreamed throughout the ministries. Zambia has disability policies in place ensuring the rights of persons with disabilities (PWD) but they are not being implemented effectively.

The purpose of our research is to evaluate methods of disability mainstreaming at a national and community level in Zambia. This was done by reviewing existing literature on the current status of inclusion of PWID at a community level, distributing a survey to evaluate the current attitudes towards PWID, and conducting interviews with disability stakeholders in Lusaka, Zambia.

We found that at a national level, the current method of appointing disability Focal Point Persons (FPP) to mainstreams disability issues throughout the ministries is not effective. Disability is a cross-sectional issue that falls under the jurisdiction of multiple ministries and needs to be treated as such. We also weigh the benefits and disadvantages of having a Ministry of Disability. At a community level, we discuss the importance of using existing infrastructure in the community including utilizing community based rehab, community health assistants, and social workers. We also mention the important role that International Day of Persons with Disabilities (IDPD), churches, Disabled People's Organizations (DPOs), parents, PWID, and training has in community sensitization. Overall, this paper looks at how attitudes towards intellectual disability can be changed at a national and community level through improved sensitization and mainstreaming.

Abbreviations

CBR	Community Based Rehabilitation
CHA	Community Health Assistants
CHSZ	Cheshire Homes Society of Zambia
CHW	Community Health Workers
CSO	Central Statistical Office
CSOs	Civil Society Organizations
DPO	Disabled People's Organizations
DRW	Disability Rights Watch
DSFZ	Down Syndrome Foundation of Zambia
FBO	Faith Based Organization
FOB	Federation of the Blind
FPP	Focal Point Person
ID	Intellectual Disabilities
IDPD	International Day of Persons with Disabilities
ILO	International Labour Organization
IRB	International Review Board
MHUNZA	Mental Health Users Network of Zambia
PWD	Persons with Disabilities
PWID	Persons with Intellectual Disabilities
SAIPAR	South African Institute for Policy and Research
SCT	Social Cash Transfer

UNCRPD	UN Convention on the Rights of Persons with Disabilities
UNZA	The University of Zambia
WHO	World Health Organization
ZACALD	Zambia Association for Children and Adults with Learning Disabilities
ZAFOD	Zambia Federation of Disability Organizations
ZAPCD	Zambia Association of Parents for Children with Disabilities
ZAPD	Zambia Agency for Persons with Disabilities
ZGF	Zambian Governance Foundation
7NDP	Seventh National Development Plan

Introduction

In Zambia, negative, stigmatizing attitudes towards Persons with Intellectual Disabilities (PWID) at a community and national level inhibit access to equal education, employment, and social opportunities. Consequently, PWID are not given the same opportunities to live a fulfilling life as a person without a disability. Zambia has theoretical policies in place that should prevent discrimination and stigmatization towards PWID. For example, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was ratified by Zambia in 2010. Zambia also passed the Persons with Disabilities Act No.6 in 2012, reaffirming the rights of PWID. The problem is that these policies are not being put into practice.

Policies alone cannot change attitudes if they are not implemented. Many stigmatizing attitudes originate from the traditional beliefs that IDs come from a supernatural cause, like witchcraft (Mckenzie et. al, 2013). In general, those who are older and less educated are more likely to hold these beliefs (Kisanji, 1998). Because of shame and fear from the community, families tend to hide PWID in their homes, decreasing PWID visibility and inclusion within the community.

Furthermore, disability issues are not a national priority. Currently, the Zambia Agency for Persons with Disabilities (ZAPD) within the Ministry of Community Development and Social Welfare (MCDSW) is the primary government entity responsible for informing the public on disability issues and creating a supportive society (ZAPD, 2017). Unfortunately, their presence has a limited impact on the lives of PWID and many of the policies are not implemented down to a community level.

Existing research on ID recommends that public awareness and understanding need to increase in Africa to improve the lives and wellbeing of PWID (Mckenzie et. al, 2013). The problem is the existing literature does not describe how this can be achieved, only that it is necessary for equality. This paper adds to existing research by analyzing literature, reviewing different methods for community and national level ID sensitization, and making recommendations on ways to implement ID mainstreaming.

The goal of this paper is to evaluate disability mainstreaming at national level in the ministries, focusing on the disability focal point person (FPP) implementation and ZAPD strategies for disability inclusion. We also explore the debate on whether or not a Ministry of Disability should be created in Zambia. At a community level, we review the current status of attitudes towards IDs and describe the local language issue of only derogatory terminology being available to refer to PWID. We elaborate on methods for community

sensitization and disability mainstreaming described by stakeholder interviews. This includes Community Based Rehabilitation (CBR), Community Health Assistants (CHA), Social workers, training opportunities, utilizing the International Day for Persons with Disability, and understanding the role that DPOs, parents, and PWID have.

Literature Review

In 2015, the central statistical office found a 7.2% prevalence rate or 1,080,000 people living with disabilities in Zambia (preliminary results from National Disability Survey) (ZAPD, 2017). Of that population, it is currently unknown how many are people with ID. ID is the reduced ability to understand new information and apply new skills (WHO, 2017). The original definition incorporated IQ scores; an IQ test score about 70 indicates that an individual has an ID (American Association on Intellectual and Developmental Disabilities, 2010) but that definition has changed from a scientific approach to a human-rights based approach. The most common types of ID are Down Syndrome, Cerebral Palsy, and Fragile X syndrome.

National Policies

Zambia has national policies and government entities in place that are responsible for integrating Persons with Intellectual Disabilities (PWID) into society. In 2010, Zambia ratified the UNCRPD shifting the approach to disability to be more human rights based. The Persons with Disabilities Act, passed in 2012, aimed to increase the participation of PWD through equal opportunities in the civil, political, economic, social and cultural spheres. This act also gives PWD the right to not be called derogatory names because of their disability. The problem is these rights are not being respected by community members and because of this, many barriers are placed on PWDs.

Barriers Faced by PWD

Although policies are present, there are multiple barriers faced by PWDs preventing them from inclusion. Negative attitudes exist towards PWDs and some people worry that inclusion will affect the achievements of people without disabilities (Scior, Hamid, Hastings, Werner, Belton, Laniyan, Patel & Kett, 2015) Traditional beliefs influence current attitudes; some believe that PWD are a result of witchcraft or a punishment from God for misbehavior from parents. Families tend to hide family members with ID because of shame that comes from these traditional beliefs (Mung'omba, 2008).

Services

PWD have the right to equal opportunities but they have difficulty accessing services. Due to lack of funding, negative attitudes, and lack of participation in decisions that affect their lives, PWD have poorer health, lower education, less economic participation and poverty rates (WHO, 2011). PWDs are one of the most marginalized groups globally because of social exclusion. It's harder for them to get access to disability organizations. Families of

PWDs need attention as well since they face economic stress. More investment needs to be put into the management of services available (McKenzie, McKonkey and Adnams, 2013).

Currently, PWD are receiving some financial support through social cash transfer programs which the Ministry of Community Development and Social Welfare (MCDSW) is in charge of. When the social cash transfer (SCT) started, the original requirement was for the aged, who were unemployed. The requirements expanded to include PWDs. Families get paid 70 kwachas bi-monthly and families of PWD get paid twice that amount bi-monthly. Community workers work with ministry staff to identify those who are vulnerable. Once people are on the SCT program, they stay in the program for the rest of their life.

There was an evaluation of SCT in 2014 and the results were successful. During the 30-month period, nearly all the recipients received their payments and most households were kept up to date on when the payments were arriving (UNICEF, 2014). The MCDSW has goals of moving the cash transfers to e-payments and beneficiaries will withdraw their payments from ATMs. The ministry also wants to expand the number of beneficiaries on SCT. Currently there are 78 districts included in the program and the goal is to have 106 districts included (Minister of Community Development and Social Welfare, 2016).

Education

The National Policy on Education of 1996 states that every individual has the right to education, regardless of personal circumstances or capacity (ILO, 2013). As of 2017, there are 24 special education schools and 220 special education units within mainstream schools (ZAPD, 2017).

Available statistics from Central Statistical Office (CSO) indicate that Zambia has a total of 50,238 pupils with ID in grades 1-9, and 878 pupils with ID in grades 10-12. There is a total of 32,752 male pupils and 18,364 female pupils giving a total of 51,116 pupils with ID (Ministry of Education policy plan, 2009). According to ZAPD 2017 Policy Statistics, the literacy rates for PWDs is 58.6% compared to the average of 70.2%. This is due to the fact that primary education is the highest level of education attained by the majority of PWDs. 34.4% PWDs never attended school compared 20.9% of those without disabilities (ZAPD, 2017). Transportation can be an issue for students so many drop out of school. Due to lack of resources, there also is not enough support in normal classrooms to accommodate PWD.

Placing students with disabilities in inclusive classrooms would be ideal; teachers would have to go through disability training in order to be prepared and provide the support needed. According to the Persons with Disability Act of 2012, all primary school teachers must take a class on special education but it's unclear if this law is in effect. On the other hand, the severity of the disability has a large impact on how students with ID will actually

behave in an inclusive classroom. The ratio of students to teachers (48:1) is already high so it would be difficult for teachers to spend extra time on the students with intellectual disabilities. Teachers agree that there needs to be more information and expertise. For those who have members in their family with a disability, or closely know someone with a disability, they are more equipped to include students with disabilities in their classroom (Subban & Sharma, 2005).

Employment

In Zambia, many employers do not hire PWDs because they don't think it will be economically profitable for their companies. (ILO, 2013). Negative attitudes and perceptions from employers create discrimination and barriers for PWDs. Employers tend to concentrate on one's outlook than the skill and diligence that PWD have (Chanda, 2011). Contrary to popular belief, hiring PWDs is beneficial for both employers as well as PWDs. Businesses who employ three or more PWD get a tax rebate incentive making it economically favorable (Mwale, 2003). For PWDs, their attitudes improve when working in a welcoming environment where they don't face discrimination or stigma.

PWIDs working in an inclusive environment developed positive self-images and no longer felt 'disabled.' (Knox, Mok & Parmenter, 2000). In order to obtain an inclusive workplace, staff members have to be trained or else they might still have negative misconceptions towards PWDs. Before PWDs find employment, they need to undergo proper training. Inappropriate social and emotional behaviors can be significant barriers to successful employment (ILO, 2013). Vocation training and market analysis should be done to see the precise skills that are needed. Independent living and social skills are also important to achieving successful employment (Koistinen, 2008). Employing PWDs is slowly becoming more common but many PWD and their families remain economically vulnerable and unemployed (Mung'omba, 2008).

Documented Recommendations for Eliminating Stigma

False and harmful beliefs prevent PWD from participating in society. Many of the negative attitudes and misconceptions towards PWDs come from the lack of awareness. In order to raise awareness, these recommendations were given. There should be participation in social, cultural and religious activities in the community, with the goal being to overcome stigma that excludes PWIDs. Parents and families of PWIDs should be included as well in order to help show the community positive images of PWIDs (McKenzie, McKonkey and Adnams, 2013).

Another measure that can be taken is to have more school based awareness about disability. Disability rights awareness should be included in all such education programmes

so that children can be reached at an early age. Teachers should be trained on disability and how to accommodate students with disabilities. Having this human right based approach will help combat stigma and discrimination towards PWD (UN Division for Social Policy Development and Department of Economic and Social Affairs, 2016).

All the literature gathered stated that a gap is missing between policy and implementation at a community level and the even though the recommendations were to raise awareness and change community attitudes, there wasn't much literature on how specifically to do so.

Moving away from policies and current attitudes, focus was shifted towards disability training toolkits to discover what methods could be used to sensitize people on disabilities. Civil society organizations in Zambia underwent disability mainstreaming toolkits which focused on transitioning disability from the medical model to the social model. The medical model views disability as a medical issue that can be fixed; the individual is the problem. The social model, on the other hand, views society as the issue and focuses on inclusion (Gilbert, 2013). In the Toolkit on Disability for Africa, a session sheet for trainers was made to promote participation in everyday life. The training workshop was composed of two sessions. The first session, 90 minutes long, 20 minutes of which a presentation is given about the obstacles to participation in political and public life for PWD. The rest was about group work and a summary discussion. These training sessions occurred over the course of two days (Gilbert, 2013). There weren't any evaluations though to see the effect of the toolkits.

Methods

In this paper, we explore the current status of attitudes towards ID and evaluate methodology recommended for sensitization and mainstreaming at a community level. At a national level, we review the status of disability mainstreaming throughout the ministries including ZAPD's current approach on informing the public on disability awareness and inclusion. To do this, we reviewed relevant literature and conducted semiformal interviews with stakeholders. We interviewed 15 stakeholders, either in person or by phone including representatives from the Ministry of Community Development and Social Welfare (MCDSW), the Mental Health Users Network (MHUNZA), UTH Special Needs School, Zambia Agency for Persons with Disabilities (ZAPD), Zambia Federation for Disability Organizations (ZAFOD), Zambia Association for Children and Adults with Learning Disabilities (ZACALD), Cheshire Homes Society of Zambia, Disability Rights Watch (DRW), and Down's Syndrome Foundation of Zambia. These stakeholders were found in collaboration with the SANI Foundation and South African Institute for Policy and Research (SAIPAR). The literature review included existing information on the status of inclusion of PWID at a community level. To evaluate the current attitudes towards PWID in Zambia, we created a survey composed of 17 multiple choice questions. The survey was sent out through the mailing list from SANI Foundation. It was also given to a convenience sample of 15 UNZA students and individuals from the stakeholder organizations we interviewed with. This research was completed in Lusaka, Zambia during June and July of 2017.

Current Attitudes Towards PWID

All interviewed stakeholders confirmed that the current attitudes towards PWID are negative in Zambia. Some thought that PWID are feared because of a lack of knowledge and understanding of the struggle PWID face.¹ Others thought that cultural beliefs were to blame, such as the belief that PWID are possessed and their condition is the result of a punishment on the family.² This results in PWID being brought to traditional healers or churches to be prayed for.³ PWID are also not treated equally within their families. They are kept home and not given the same opportunities for education as other siblings, resulting in not receiving the support they need.⁴ PWID are also stigmatized during public transportation⁵ and their autonomy and decision making is limited in community settings like hospitals and banks.⁶ PWID are not only looked down upon in their own community but also the disability community in general. They do not think that PWID can make useful contributions.⁷

Our survey results confirmed the perception that general community attitudes are negative towards IDs and that families shelter their child with an ID. The most popular answer for why community attitudes were negative was that PWID are seen as less human because they do not possess the same intellectual abilities. Another popular answer was PWID do not have the right social abilities to fit into society. The most common response for how PWID can be more included in the community was church leaders and community members need to promote inclusion. Also promoting inclusive education at a young age was a common response along with the government should provide more services. The people surveyed also thought that church, family and friends' opinions were key influences in changing mindsets, something that will be considered when we discuss community results.

¹ Personal communication with a representative from ZGF and a representative from CHSZ

² Personal communication with a representative from MHUNZA and a representative from FOB

³ Personal communication with a representative from MHUNZA

⁴ Personal communication with a representative from ZAFOD and a representative from DRW

⁵ Personal communication with a representative from UTH Special School

⁶ Personal communication with a representative from ZAFOD

⁷ Personal communication with a representative from ZAFOD

Resolving Inclusion Barriers

National Level

Mainstreaming ID Throughout the Ministries

The level of disability mainstreaming that occurs throughout the ministries is dependent on the political climate and funding available at that time. ZAPD made statements in their Strategic Plan for 2017-2021 that they are shifting their focus away from providing services to PWD towards moving this responsibility to other stakeholders through mainstreaming. (ZAPD, 2017) Their primary method for this is using decentralized Focal Point Person (FPP) system, required by the UNCRPD. A FPP is appointed to receive disability training, mainstream disability issues within their ministry, and sensitize their coworkers. The problem is this position is unpaid and not well known even among the MCDSW, compared to FPP for gender and HIV. Also, non-decision-making people often receive this training, making it difficult for it to be translated into practice.⁸

Funding to the ministries for disability consideration in their programming has been increasing⁹ but there is concern on accountability. More effective budget tracking down to the district level is needed to see how the funds are being implemented.¹⁰

Disability is a cross-sectional issue that covers the jurisdiction of multiple ministries such as the Ministry of Justice and the Ministry of Education. PWID are vulnerable to sexual violence because perpetrators think they will not testify¹¹. They are also not given equal access to justice in the legal system. The Victim Support Units in police stations do not have the training and resources to accommodate PWID, who are often deemed unable to instruct a lawyer or stand trial (ZAPD, 2017). Also, some laws in place, such as trespassing laws, make PWIDs vulnerable to being arrested.¹²

Many of the stakeholders we interviewed thought changes needed to be made towards education to change attitudes, falling in the jurisdiction of the Ministry of Education. Unfortunately, the Seventh National Development Plan (7NDP) released did not include disability into the education goals (Ministry of National Development Planning, 2017). Zambia needs to solidify its education goals for disability before change can happen.¹³ It was recommended by the stakeholders that the curriculum needs to create more disability

⁸ Personal communication with a representative from ZAFOD and a representative from DRW

⁹ Personal communication with a representative from MCDSW and a representative from DRW

¹⁰ Personal communication with a representative from DRW

¹¹ Personal communication with a representative from ZAFOD

¹² Personal communication with a representative from ZAFOD

¹³ Personal communication with a representative from DSFZ

awareness through a human right based approach¹⁴ and more services need to be available in schools to increase PWID visibility and acceptance.¹⁵ Disability issues apply to multiple ministries and need to be mainstreamed as such.

Representative from the DSFZ, an organization based in the eastern province, said that the ZAPD's presence should be felt throughout Zambia but currently this is not happening. The ZAPD is the primary agency in the government responsible for informing the public on disability issues and creating a supportive society. Their fourth outcome for the 2017-2021 Strategic Plan is to create a well-informed society supportive of disability issues. The 6 main strategies proposed to do this are involving faith based organizations (FBOs), increasing community awareness and sensitization at a national, provincial, and district levels through radio and TV programs, theater activities and sensitizing at least 2 chiefs per district, implementing a disability role model or "champion" strategy, lobbying for the inclusion of disability in school curriculums, engaging the private sector to include disability within their operations, and using print and electronic media to engage the public, including having a disability annual media awards starting in 2018.

Radio was the most common answer on how our stakeholders thought they could reach a wide population¹⁶ since radios are in cars, phones, and accessible to rural populations¹⁷. More needs to be done besides radio programming to reach more people¹⁸. Stakeholders also mentioned youth with ID getting involved in the community through sports, poetry¹⁹, and holding community events with drummer and cultural groups²⁰.

Ministry of Disability Debate

Currently, disability issues are not being thoroughly mainstreamed throughout the ministries. This brings up the debate on whether all the responsibility should stay with ZAPD within the MCDSW or if a new Ministry of Disability should be created. The argument against the creation of the new ministry points out a separate ministry might lead to exclusion and isolation of PWD while additionally preventing disability mainstreaming.²¹ Instead it is more important to promote inclusion within other ministries since disability is

¹⁴ Personal communication with a representative from DRW, a representative from FOB and a representative from MHUNZA

¹⁵ Personal communication with a representative from DRW and a representative from ZACALD

¹⁶ Personal communication with a representative from FOB and a representative from CHSZ

¹⁷ Personal communication with a representative from DRW

¹⁸ Personal communication with a representative from ZAPD

¹⁹ Personal communication with a representative from DRW

²⁰ Personal communication with a representative from CHSZ

²¹ Personal communication with a representative from ZAFOD, a representative from DRW and a representative from CHSZ

a cross-cutting issue that spreads across multiple ministries.²² Disability needs to be mainstreamed within the ministries the same way it should be mainstreamed throughout society.²³ A counter argument for a Ministry of Disability emphasized that it would be beneficial to have all of the disability issues focused into one ministry. It would receive its own funding that would be easier to track and ensure it is going towards disability issues and not be mishandled.²⁴ Increasing funding stability would be beneficial since the current ZAPD does not have an endowment to continue operations if funding is unexpectedly interrupted.

Looking at the creation of the Ministry of Gender in 2012 can give some insight on potential consequences of the creation of the Ministry of Disability. Ministry of Gender came about from gender mainstreaming. Like the Ministry of Gender, a Ministry of Disability would be using the infrastructure and resources of MCDSW.²⁵ Plus representatives from the MCDSW thought it could easily be placed into another ministry if the political climate changed. Like disability, gender issues span across the jurisdiction of multiple ministries. Other ministries do not take the Ministry of Gender seriously (Lusaka Times, 2017) which could have negative consequences if other ministries not properly reporting to the Ministry of Gender.

Community Level

Sensitization and Mainstreaming

Use Existing Infrastructure

One method for mainstreaming disability issues at a community level is to use existing infrastructure available.²⁶ This helps promote inclusion by using well established community resources and not creating separate ones that can be segregating. Using existing infrastructure can also be more efficient.

One avenue to utilize is community health assistants (CHAs) from the Clinton Health Foundation. ZGF has been working on making disability training available to CHAs²⁷. CHAs already receive training on topics of sanitation and health so additional disability sensitization training could be fit into the curriculum. In addition, CHAs are respected

²² Personal communication with a representative from ZACALD

²³ Personal communication with a representative from CHSZ and a representative from DRW

²⁴ Personal communication with a representative from DSFW

²⁵ Personal communication with a representative from MCDSW

²⁶ Personal communication with a representative from ZGF

²⁷ Personal communication with a representative from ZGF

members of the community and can play a role in ID awareness as well as debunking popular ID origin myths. It was also recommended to use sensitivity training for social workers to increase their impact.²⁸

Another method of disability mainstreaming that utilized existing resources is Community Based Rehabilitation (CBR). According to the WHO, CBR is “a strategy within general community development for the rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all people with disabilities” (Achu et al., 2010). This is broken down into five categories: health, education, livelihood, social, and empowerment. As of 2017, there are three piloted CBR programs in Zambia: Livingstone, Kazungula, and Zimba. Initial results are supporting upscaling of the programs (ZAPD, 2017). Advocacy groups are involved in CBR to support inclusive activities in the community and promote early identification of PWID.²⁹ CBR also focuses on making sure community services are accessible for those with disabilities.³⁰ They run awareness programs involving parents, CSOs and people dealing directly with children.³¹

Churches are another possible avenue within the community that can be used to change attitudes towards ID. They are well established within the community and, as stated previously, our survey found that church was one of the top influences on individual attitudes. Many of our stakeholders thought that the church was a good place for parents to receive support and sensitize the community.³² The ZAFOD recommends self-advocacy disability groups should visit churches to sensitize the leaders on the problems PWD face. Both Christians and Muslims need to be involved in this process.³³

The Language Problem

One additional barrier PWID face towards inclusion is the language used to describe their disability. In many of the local languages in Zambia, like Nyanja and Bemba, only derogatory terms exist to describe PWID.³⁴ The Disabilities Act of 2012 prohibits derogatory language but it is still used in communities and the media because there are not alternative words to use. The problem is language is difficult to change. It takes a long time

²⁸ Personal communication with a representative from MHUNZA

²⁹ Personal communication with a representative from ZAFOD

³⁰ Personal communication with a representative from CHSZ

³¹ Personal communication with a representative from DRW

³² Personal communication with a representative from UTH Special School and a representative from ZAPD

³³ Personal communication with a representative from ZAFOD

³⁴ Personal communication with a representative from ZACALD, a representative from MHUNZA and a representative from DRW

and success is not guaranteed.³⁵ PWID have the right to be spoken about respectfully³⁶. Although the words used may have been around for many years and are imbedded into the culture, culture cannot be used as a justification for human rights violations (UN Toolkit on Culture, Beliefs, and Disability, 2016).

One solution proposed by our stakeholders was to have the current words used documented and have new words that respectively describe PWID agreed upon by DPOs.³⁷ Once the words are agreed upon, journalists will need to be trained on the new language and stigmatizing statutes in the government will need to be amended (UN Toolkit on Culture, Beliefs, and Disability, 2016). Media is especially important for portraying PWID positively and respectfully, something that is not currently happening (MHUNZA).

One example of successful change in language is with the MCDSW National Policy of December 2015. The terminology was changed from “persons living with disabilities” to “persons with disabilities” focusing more on the person and less on the condition.³⁸ Changing language will not be an easy task but it is necessary to uphold the rights of PWID.

Role of DPOs, PWID, and Parents

At a community level, it is essential that DPOs, PWID, and parents work together to change community attitudes. Throughout our stakeholder interviews, it was a common belief that community attitudes can be changed by increasing the visibility in the community of PWID and DPOs. To increase visibility, it was recommended by our stakeholders for DPOs to increase community outreach. Common outreach activities include holding fundraisers with sporting events, drama, dances, and poetry,³⁹ inviting the public to open house days,⁴⁰ and selling goods in the market.⁴¹ A representative from ZAPD thought there was a very heavy assumption from the community that people expect the government to be responsible for educating the community when they thought the DPOs need to have a greater responsibility in informing the community around issues surrounding PWD.

Another common response from stakeholders was increasing the visibility of “Disability Champions,” PWD who showcases their success as a positive role model for other PWDs,

³⁵ Personal communication with a representative from FOB

³⁶ Personal communication with a representative from CHSZ

³⁷ Personal communication with a representative from DRW

³⁸ Personal communication with a representative from MHUNZA

³⁹ Personal communication with a representative from UTH Special School?

⁴⁰ Personal communication with a representative from FOB

⁴¹ Personal communication with a representative from SANI

their parents, and communities.⁴² Disability Champions can help create a positive image of PWID, which in return may help change community attitudes (CHSZ).

Another opportunity we found that DPOs and PWD use to increase visibility within the community is celebrating the International Day of Persons with Disabilities (IDPD) on December 3rd every year. All disabilities are recognized on this day, including ID. IDPD is an opportunity to educate community members on the rights of PWD and have high profile government officials involved (UN Toolkit on Culture, Beliefs, and Disability, 2016).⁴³ DPOs celebrate by creating booths to display their work, marching, and organizing programs.⁴⁴ They prepare speeches and songs, allowing PWD to showcase who they are to the community.⁴⁵

One method for changing attitudes in the private sector is through sensitivity training to avoid discriminatory practices. The goal is to change the way PWD are treated and viewed within the workplace through human rights based approach. The training teaches practical steps to mainstream disability. Like FPP within the ministries, one major problem with disability sensitivity training is non-decision-making people are getting the information and it is difficult for it to be translated into practice. To try to fix this, after training, an action plan is made to outline how the information will be implemented. There are also follow up visits with questionnaires to assess the status of the action plan and if the information reached the leaders of the organization.

Besides training for those working in the private sector, community members, along with a few nurses and teachers affiliated with ZAFOD help sensitize disability. The Disability Rights Watch also trains their youth disability groups on their rights as well as how to advocate for legal rights. Throughout the training and sensitization workshops, PWIDs should not be forgotten in the process. They are humans just like everyone else so they should be treated as such but sometimes they are not aware of their rights.⁴⁶ Some service providers may not be aware of the rights PWD have therefore training workshops should include sensitizing service providers so that they can change their attitudes, policies and practices.

ZACALD has done disability training for PWIDs as a pilot program which lasted from 2004-2013 and the goal of the training was to provide empowerment. The organization working

⁴² Personal communication with a representative from ZAPD, a representative from MHUNZA and a representative from CHSZ

⁴³ Personal communication with a representative from MHUNZA

⁴⁴ Personal communication with a representative from DRW

⁴⁵ Personal communication with a representative from MHUNZA and a representative from ZACALD

⁴⁶ Personal communication with a representative from ZAFOD

with ILO to train PWIDs to find employment in about 15 countries. The participants were also trained on issues surrounding legal capacities, education and independence. The struggle with the program was it was difficult finding PWIDs to train so only 15-20 people were trained in each country.⁴⁷

Many stakeholders pointed out that parents should educate other parents and community members to help them understand the challenges PWID face. When parents find special schools, they have high hopes for their children and assume that their child will automatically become the top student of his or her class. There is emphasis that each child is different and it will take time for him or her to be on the same level of someone who doesn't have a disability. Homework is given in order for parents to work with their children but there can be negative attitudes from time to time since parents are busy so they might not have the time.⁴⁸ A representative from ZAPD, said that changing mindsets starts from the family. A few DPOs spoken to stated that a goal of theirs is to make support groups because family and peer networks need to be sensitized. It's important for parents as well as their children to be empowered. One way to empower PWID is to teach family members about supported decision making, allowing for increased autonomy for decisions in their lives.⁴⁹ A continued struggle is some parents being protective and uncooperative with the training workshops, resulting in their children with IDs staying home.⁵⁰

PWID cannot be forgotten in the discussion of changing attitudes. Like parents and community members, PWID need self-advocacy training to combat stigma and stereotypes (UN Toolkit on Culture, Beliefs, and Disability, 2016). We need to include PWIDs in all levels of society⁵¹ and educate them on their rights.⁵² The ZAFOD uses local coordinators and facilitators to form self-advocacy groups. The ZACALD has also done workshops for PWID to inform them on their rights.

What is Holding Intellectual Disabilities Back?

Looking at how attitudes changed surrounding issues like HIV and gender, we tried to find out what has been holding ID back. For HIV, there was major international involvement from organizations like UNICEF. UNICEF focuses on issues like HIV, early childhood development, and social protection but not much on disability. Even within early childhood

⁴⁷ Personal communication with a representative from ZACALD

⁴⁸ Personal communication with a representative from UTH SC

⁴⁹ Personal communication with a representative from ZAFOD

⁵⁰ Personal communication with a representative from ZACALD

⁵¹ Personal communication with a representative from ZACALD

⁵² Personal communication with a representative from MHUNZA and a representative from FOB

development, the focus was mostly on education for children up to 10 years old even though many ID are found during early child development.

Gender issues have also received international attention and funding. One of the millennium development goals was to “promote gender equality and empower women.” For Zambia, it was recommended to approach this by sensitizing communities and families to value women and to get girls enrolled in school. Also, the Zambia National Gender Communication Strategy of 2010-2015 was created and distributed throughout the ministries to increase gender mainstreaming. Gender FPP system was used to increase mainstreaming and more women are appointed into government positions.

Although there are policies in place at a national level, such as the Persons with Disabilities Act of 2012, they are not being implemented into practice. In general, disability issues are not a strong government priority. The 7NDP contains limited information on disabilities compared to goals for HIV and Gender. If disability issues are to catch up to the progress being made with HIV and gender, it needs to become a national and international priority. The issue needs more exposure. Radio programs are a useful way of spreading information. If DPOs were able to use multiple radio stations to insert a quick pitch about ID during commercials that would help raise awareness.

Because of ongoing stigma, families do not want to admit that they have a child with an ID. PWID also face stigma from the general disability community. There needs to be ID acceptance within the family structure and the disability community before it can be translated into inclusion and acceptance within the general community.

Recommendations

Community Level

Intellectual disability is a multi-faceted issue that should be approached from different angles. There must be involvement from the government, educational institutions, churches and families. Disability mainstreaming will need more than one solution. The most beneficial thing that can be done to help PWID is to empower them. Their families are the strongest support they have. Sensitizing families on the negative consequences of keeping them at home and hidden from the community will in turn empower PWID. Families also need to be aware protecting their family member with an ID from the negativity in the community can infringe on the autonomy of a PWID. There needs to be increased awareness for supported decision making giving a PWID more control over their life.

Use Existing Infrastructure

As previously mentioned in this paper, there is already infrastructure within the community set in place that if given more funding and training could promote inclusive behaviors and awareness of PWID. For instance, the CBR programs being implemented are a great opportunity to use existing resources to support PWID in the community. Respected members of the community such as CHAs and social workers should be targeted for disability sensitivity training because of the influential role they have in the community. Also utilizing IDPD provides an opportunity to increase ID awareness, unite DPOs and positively influence community attitudes.

Training

Disability training aims to sensitize people about disability. But, as previously mentioned, the people participating in the disability training sessions are not in decision making positions. The target should be to train bosses, directors and other staff in decision-making positions. When training does occur, there needs to be action plans to make goals for mainstreaming within the organization and an evaluation to see whether or not changes are being implemented.

Language

To combat the issue of only derogatory language being available to describe PWID, DPOs need to come together to review the current terms used for PWID and brainstorm new words that are respectful and have the potential to stick. Hopefully, with awareness campaigns informing the public and the media on the new terminology, the derogatory terms can be replaced with the new respectful words and the rights of PWID will be upheld.

National Level

Disability Mainstreaming within the Ministries

Currently, disabilities are not being thoroughly mainstreamed throughout the ministries. The disability FPP needs to be paid like the FPP for HIV and gender. Also, a person with decision-making power should receive the training, increasing the odds of effective implementation of the training. Increased evaluation is needed to ensure funds meant for disabilities in other ministries are being used for disabilities. Closer monitoring needs to be done to find any additional barriers preventing the implementation of disability mainstreaming.

International Examples of Disability Mainstreaming within Ministries

A potential opportunity for further research is examining international examples of disability mainstreaming within governments. It could be beneficial for Zambia to learn what has and has not worked in other countries when approaching disability mainstreaming throughout its own government. The Zambian government should consider other disabilities ministries that have been created internationally at evidence when further evaluating the Ministry of Disability debate.

Closing

Our research has shown that although there has been some progress, more work needs to be done at both the national and community level to achieve inclusion and acceptance. Mainstreaming ID needs the involvement of multiple groups mentioned above. Community stigma towards PWID will be challenging to change but with increased disability mainstreaming from parents, advocates, community members, and DPOs PWID will face fewer barriers to community acceptance. ID has slowly gained some awareness over the years and, if provided more funding and international support, the current DPOs and NGOs in place would be able to provide more services and support to speed up the process.

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References

- Achu, Kamala, Jubah, Kathy A., Brodtkorb, Svein et al. 2010. *Community-Based Rehabilitation (CBR) Guidelines*. World Health Organization.
<http://apps.who.int/iris/bitstream/10665/44405/9/9789241548052>
- American Association on Intellectual and Developmental Disabilities. 2010. 'Definition of Intellectual Disability'
- Chanda, Mulenga M. 2011. *A Critical Analysis of the Law Governing Persons with Disabilities in Zambia with Particular Reference to Employment*.
<http://dspace.unza.zm:8080/xmlui/bitstream/handle/123456789/2114/mulengachanda00001.PDF?sequence=1>
- Gilbert, Maureen. 2013. *Disability Mainstreaming Toolkit for Civil Society Organisations in Zambia*. Zambian Governance Foundation.
http://197.220.255.230:8080/jspui/bitstream/123456789/324/2/ZGF_Disability
- Inclusion International. 2006. *Hear Our Voices: A Global Report: People with an Intellectual Disability and Their Families Speak out on Poverty and Exclusion*.
- International Labour Organisation. 2013. *Inclusion of People with Disabilities in Zambia*.
http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_115100.pdf
- Kisanji, J. 1998. The March Towards Inclusive Education in Non-western Countries: Retracing the Steps. *International Journal of Inclusive Education*. 2(1): 133-151
- Knox, Marie, Mok, Magdalena & Parmenter, Trevor R. 2000. 'Working with the experts: collaborative research with people with an intellectual disability.' *Disability & Society*. 15(1):49-61
- Koistinen, Mari. 2008. Understanding experiences of vocational training and employment for persons with learning disabilities in Zambia: Lessons for the future (Helsinki, FAIDD Finnish Association in Developmental Disabilities).
- Lusaka Times. 2017. 'Mutati treats my Ministry of Gender like Cinderella Ministry, He Should Study PF Manifesto-Lungu'

<https://www.lusakatimes.com/2017/03/09/mutati-treats-ministry-gender-like-cinderella-ministry-study-pf-manifesto-lungu/>

McKenzie, Judith A., McKonkey R., and Adnams C. 2013. *Intellectual Disability in Africa: Implications for Research and Service Development*. 35(20):1750-5
<https://www.ncbi.nlm.nih.gov/pubmed/23350758>

Minister of Community Development and Social Welfare. 2016. MCDSW Ministerial Statement on the Scale Up of the Implementation of the Social Cash Transfer Programme.

Ministry of National Development Planning. 2017. Seventh National Development Plan: 2017-2021.

Mung'omba, James. 2008. 'Comparative Policy Brief: Status of Intellectual Disabilities in the Republic of Zambia'. *Journal of Policy and Practice in Intellectual Disabilities*, 5(2):142-144

Mwale, Fred M. 2003. *Intellectual Disabilities: JFY 2003 Country Report Zambia*.

Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, M., & Kett, M. 2015. *Intellectual Disabilities: Raising Awareness and Combating Stigma—A Global Review*.

Subban, Pearl and Sharma, Umesh. 2005. 'Understanding Educator Attitudes Towards the Implementation of Inclusive Education'. *Disability Studies Quarterly*, 25(2).

UNICEF. 2014. *Social Cash Transfer Programme Impact Evaluation: 30-Month Report for the Child Grant*.
https://www.unicef.org/zambia/Social_Cash_Transfer_Programme_Impact_Evaluation_in_Zambia_30_Month_Report_for_the_Child_Grant.pdf

United Nations Division for Social Policy Development and Department of Economic and Social Affairs. 2016. *Toolkit on Disability for Africa: Participation In Political and Public Life*.
<http://www.un.org/esa/socdev/documents/disability/Toolkit/Participationin-Political-Publiclife.pdf>

United Nations Division for Social Policy Development and Department of Economic and Social Affairs. 2016. *Toolkit on Disability for Africa: Culture, Beliefs and Disability*.

<http://www.un.org/esa/socdev/documents/disability/Toolkit/Cultures-Beliefs-Disability.pdf>

World Health Organization. 2016. 'Definition: Intellectual Disability.'

<http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability>

World Health Organization. 2011. *World Report on Disability*.

http://www.who.int/disabilities/world_report/2011/report.pdf

Zambia Agency for Persons with Disabilities. 2017. Strategic Plan 2017-2021: Promoting Inclusive and Sustainable Development.

Appendix: Limitations

Our biggest limitation was time. We had only 8 weeks to complete our research. We also were only able to focus on interviewing people in Lusaka, leaving out rural areas which make up the majority of Zambia. We conducted 15 expert interviews but we were unable to interview all people we wanted like with representatives from church organizations or the Zambia Agency of Employment of Persons with Disabilities. We had a limited sample for our survey.