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The Accessibility of Sexual and Reproductive Health Rights
Information for People with Intellectual Disabilities in Zambia

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Abstract

In Zambia, the sexual and reproductive health rights (SRHR) of people with intellectual disabilities (PWIDs) have received little attention, an issue that has been intensified by the vulnerability of PWIDs (Mckenzie et al., 2012). PWIDs are at a greater risk for being sexually abused and receiving HIV/AIDS, for this reason it is all the more important that PWIDs have access to their SRHR (Sullivan et al., 2000; Nora Groce, 2005). This vulnerability arises from several risk factors, including poverty, illiteracy, discrimination, and stigma (Nora Groce, 2005). PWIDs are often not provided with information on their SRHR due to the belief that they are asexual (Mckenzie et al., 2013). When PWIDs are provided information on their SRHR, it is often presented in a format that they are unable to understand (Chapman et al., 2015). While Zambia has policies in place to protect people with disabilities (PWDs), many of these policies are only on paper; they are rarely enforced (Zimba, 2016).

The purpose of this research was to explore existing institutions and systems available to PWIDs to inform them of their SRHR. Results were found through a literature review and semi-structured interviews in Lusaka, Zambia with stakeholders relevant to this issue, and recommendations were drawn from these results. It was found that in the general population there is stigma and a lack of awareness regarding PWIDs, and that PWIDs are vulnerable to sexual abuse and HIV/AIDS, confirming what was found in the literature review. Additionally, many PWIDs were unaware of information regarding sexual health, or had many misconceptions. PWIDs could potentially receive information from family members, the education sector, education outreach, or through the healthcare sector; however, none of these groups were able to provide comprehensive information for various reasons, including a lack of resources, finances, time, information, or staff, or for cultural reasons. Furthermore, there were gaps between policy and practice, particularly in the education and health sectors, where the information PWIDs were receiving were not to the standard they were supposed to be receiving. Finally, it was found that there was a lack of communication and collaboration among relevant stakeholders. From these results, recommendations were made for parents and families, the education sector, the health sector, and for increased collaboration among organisations.

Acronyms

AATAZ	Anti-AIDS Teacher's Association of Zambia
AIDS	Acquired Immune Deficiency Syndrome
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Central Statistics Office
DPO	Disabled Persons Organisation
HIV	Human Immunodeficiency Virus
ID	Intellectual Disability
IRB	Institutional Review Board
MCDMCH	Ministry of Community Development, Mother and Child Health
MoGE	Ministry of General Education
MoH	Ministry of Health
NGO	Non-Governmental Organisation
PPAZ	Planned Parenthood Association of Zambia
PWD	Persons with Disabilities
PWID	Persons with Intellectual Disabilities
SHN	Special Hope Network
SNDP	Sixth National Development Plan
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health Rights
TESS	Teacher Education and Special Services
UN	United Nations
UTH	University Teaching Hospital
WHO	World Health Organisation
ZAPCD	Zambia Association of Parents for Children with Disabilities
ZAPD	Zambia Agency for Persons with Disabilities

Introduction

In their lifetimes, PWIDs are at a higher risk to be sexually abused or to contract HIV/AIDS than those without intellectual disabilities (IDs; Sullivan et al. 2000; Nora Groce 2005). This phenomenon is most likely because there is great overlap between the social by-products associated with IDs and the risk factors associated with HIV/AIDS and sexual abuse (Nora Groce, 2005). These overlapping social concerns and risk factors include poverty, illiteracy, stigma, and discrimination (Nora Groce, 2005). Because of these realities, the sexual health of PWIDs and a PWID's awareness of his or her own sexual rights is an important topic. This topic especially relevant in a country like Zambia because of the high prevalence of HIV and the high stigma and discrimination associated with intellectual disabilities.

Worldwide, the sexual and reproductive health rights (SRHR) of PWIDs have been neglected in part because of the stigma and exclusions associated with IDs, and because of the various myths suggesting that PWIDs are asexual or do not have sexual needs (Mckenzie et. al, 2013). Consequently, there is little information available to PWIDs about their own sexual health. In the cases where sexual and reproductive health (SRH) information is available and presented, the format in which it is provided is often presented in a way that PWID cannot understand (Chapman et. al, 2015). This situation is amplified in Zambia due to the general lack of awareness, information, and statistics regarding the state of people with disabilities (PWD), as there have been few studies and awareness campaigns about disabilities in Zambia. Within the realm of disabilities, even less is known about IDs, as PWIDs and people with mental health disorders are some of the most stigmatized groups in Zambia. As stated in the Zambian constitution, access to SRH information is a basic right for all persons and thus all members of the population, even those with disabilities, should be provided with the same knowledge even if it is through different mechanisms or formats (Zam. Const. amend. CXII, sec. IX). This paper thus examines the Zambian institutions and systems in place to address the SRHR of PWIDs.

After extensive research on the topic, we found that although there are some systems and institutions in place, mostly within the education sector, there are still wide gaps when informing PWIDs of their SRHRs; these gaps are apparent when looking at the quality and quantity of SRH information PWID receive. Our research demonstrated that both parents and the healthcare system play little role in informing PWIDs of their SRHR. In order to reach this conclusion, we performed a literature review on the existing research. We looked at both international research related to the access of SRH information for PWID and research specific to disabilities in Zambia. Throughout this research we followed the social model of disability; this model states that a disability is due to the way society is organized, rather than by a person's impairments or differences (Jamison, 2006). To gather results, we interviewed a variety of stakeholders in the Zambian community to gain their perspectives on how institutions and systems inform PWIDs of their SRHR. We drew our results from the literature review and the interviews. Finally, from our results, we made

recommendations on how to better adapt systems and institutions to provide PWID with adequate information about their SRH. The structure of this paper will mimic our research process. We will first expand on the methods used to conduct the research. Then we will present our findings from our literature review and interviews. Finally, we will suggest recommendations for stakeholders involved in the issue and we will conclude with a final discussion of results and recommendations.

Literature Review

The World Health Organisation (WHO, 2016) defines intellectual disability as ‘a significantly reduced ability to understand new or complex information and to learn and apply new skills’, which begins before adulthood and has lasting effects on development. Intellectual disabilities thus result in a reduced ability to cope independently. IDs can be the result of genetic abnormalities, infections occurring prior to or after birth, or trauma. IDs can also be acquired through poor antenatal care, cerebral malaria, and malnutrition (Jamison, 2006). Furthermore, children with IDs in poor families are often not seen as productive, resulting in an unwillingness to seek proper healthcare for them which can at times exacerbate the condition (Mckenzie et. al., 2013).

It is estimated that 2% of the population of Zambia has a disability (CSO, 2010). Out of the disabled population of Zambia, about 1.1% of people have an intellectual disability (CSO, 2010). The classification used to define disability for these Central Statistics Office (CSO) statistics was that of the 1980 WHO International Classification of Impairments, Disabilities, and Handicaps (Banda & Kalaluka, 2014). Under this classification, a disability is a physical or mental handicap that lasts at least six months and prevents a person from carrying out daily activities independently, or from participating fully in education, economic, or social activities (Banda & Kalaluka, 2014). Within the classification of disabilities, the CSO defined an intellectual as a disability characterised by significant limitations in intellectual functioning and adaptive behaviour, which covers many everyday social and practical skills, and originates before the age of 18 (CSO, 2010). Past estimates of disability prevalence in Zambia by the CSO have been criticised as underestimations, due to the classification methods and underreporting by households due to stigma. Worldwide, the prevalence of disability is between 10% and 12%, if this is the case in Zambia, the CSO statistics may be inaccurate and more than one million people may be living with some form of disability (World Bank, 2010). Other reports state the number of people living with disability in Zambia is approximately two million (Human Rights Watch, 2016). The ambiguity of these statistics represent the lack of attention given to people with disabilities, and the issues they face.

The issue we focus on in this research is PWIDs’ access to SRHR information. SRHR include access to sexual and reproductive healthcare and information, and autonomy in sexual and reproductive decision-making (Amnesty International, 2016). As previously stated, ‘every person in Zambia has the right to healthcare services and reproductive healthcare’ (Zambian Constitution, 2016). However, these rights of people with IDs have largely been neglected due to social attitudes acting as barriers, which prevent PWIDs from accessing these services (Scior et. al., 2015). For example, there is an assumption in Zambia that those with IDs have no legal capacity due to a perceived lack of mental capacities, and therefore may not receive proper care or information about their SRHR when accessing healthcare (United Nations: Human Rights, 2016).

Perceptions of Intellectual Disabilities

There has been a global shift in the understanding and perception of disabilities. Previously, disabilities were considered an individual, medical issue, but now there is an increasing social, structural understanding of disabilities (Jamison 2006). This change is because disabilities are the result of the interaction between a person with a health condition and the environment they live in, and promoting inclusion requires the removal of environmental barriers (World Disability Report, 2011).

Despite a general increase in awareness and understanding of disabilities, there are still some erroneous and culturally-rooted beliefs that are persistent. Among some people in Zambia, there is a belief that intellectual disabilities are the result of divine retribution or witchcraft, which can cause parents to hide children with IDs (Mckenzie et. al, 2013). The lack of social exposure interferes with potential social and intellectual development of the individual, and also contributes to stigmas against those with IDs (Mckenzie et. al., 2013; Mung'omba 2008). This exclusion is still prominent, especially in rural areas (Mung'omba 2008).

Exclusion and stigmatization are also present in schools, since students are often unwilling to accept other students with intellectual disabilities (Mung'omba 2008). However, some Zambian studies have shown that when nondisabled students interact with students with IDs, they are more likely to have a positive image of PWID than nondisabled students who do not interact with students with IDs (Ronning and Nabuzoka 1993). Findings such as this one have given life to the movement away from exclusion and toward inclusion of PWID. For example, Zambian schools are now moving in the direction of mainstreaming. Mainstreaming is the process of taking children with disabilities away from special units and placing them in classes with students without disabilities. There has also been a recent movement by religious institutions to embrace PWIDs to promote inclusion, even if historically religion saw PWID as unclean and unable to worship (Mung'omba 2008).

Sexual Abuse and HIV/AIDS

Many studies indicate that PWID are more vulnerable to sexual abuse (Davis, 2005). For example, one study found that children with disabilities are 3.4 times more likely to be sexually abused than children without disabilities (Sullivan et al., 2000) This abuse ranges from unwanted touching to rape (Davis, 2005). The increased vulnerability is believed to be due to the stigma and social exclusion tied to intellectual disabilities (Davis, 2005). Additionally, PWID often have more trouble advocating for themselves or in some cases are not aware of what is or is not an appropriate form of touching (Davis, 2005). Additionally, the virgin cleansing myth suggests that if an HIV positive individual has sex with a virgin or disabled person, they will be cured of HIV/AIDS. This leads to both the sexual abuse of PWID, and the higher prevalence of HIV/AIDS (Mckenzie et. al, 2013).

Globally, there is inadequate data and reporting of HIV prevalence in populations of disabled individuals. In Zambia, the prevalence of HIV/AIDS among 14 and 49 years old is 14% (CSO, 2007). Because research suggests that sexual abuse is more common amongst PWID, it is likely that PWID in Zambia maintain an HIV/AIDS prevalence that is greater than 14%.

There is a lack of suitable information about HIV/AIDS for people with IDs (World Bank, 2010). More specifically, teachers feel like there is no need to teach PWID about HIV/AIDS, PWID are left out of special clubs regarding HIV prevention, or there is a lack of material to appropriately teach PWID about their SRHR in schools (Human Rights Watch, 2014). Similarly, if diagnosed with the virus, because of the lack of suitable information, PWID may have difficulties following the treatment regimen (World Bank, 2010). One study found that there is disability related discrimination and communication barriers when people with disabilities access HIV services (Nixon et al., 2014). This can range from discrimination by fellow patients while waiting in queues at clinics, to discrimination by healthcare workers who are providing treatment. (Nixon et. al, 2014). Furthermore, PWID often do not receive confidential treatment at HIV clinics because a third party is needed for appointments as PWID may not be able to understand complex messages about HIV/AIDS and may need another person to help them adhere to treatment regimens (World Bank, 2010). Another barrier faced by PWID exists as the result of the cycle of poverty, disability, and HIV, where each of these factors negatively impact one another. PWID who face poverty commonly experience food insecurity, and as a result this makes it difficult to adhere to treatment regimens that may require medication be taken with food (Nixon et al., 2014)

Sex Education

Because the HIV prevalence rate in Zambia continues to be one of the highest worldwide, emphasis has been placed on educating the general Zambian population about their SRH (Kapata, 2012). The main institution through which sex education has been distributed to the general population is the education sector (Kapata, 2012). Other methods such as AIDS action club, young people peer education, and technological approaches such as the Internet and mobile phones are being used to disseminate information (Kapata, 2012). Although these methods are theoretically in use, there are still wide gaps between teacher and student knowledge (Kapata, 2012). Moreover, it is a common thought that teaching life skills might lead to increase sexual activity and promiscuity (Kapata, 2012). Thus, there is some opposition in teaching about SRH in schools, especially to younger children (Zimba, 2015). Consequently, as indicated by the National AIDS Strategic Framework annual report (2009), out of the 2,437,198 young people who were supposed to receive life skills education, only 11% were reached.

As previously discussed, there are challenges in educating the general Zambian public about their SRHR. These challenges are furthered when looking at PWID. Research

performed in Nepal, Uganda, and Kenya showed that of a group of people with disabilities, those with intellectual disabilities were least aware of their sexual and reproductive health (Tanabe et al., 2009). Additionally, because PWID are an at-risk population for HIV/AIDS and sexual abuse, it is crucial to offer sex education to this population. However, worldwide little research has been done on this topic. CHANGE, a British organisation that fights for the rights of PWID, has done research on PWID and their access to sexual education. The study found that parents and teachers believed that sex education is a right for PWID. It also found that information should be more accessible for PWID, that parents and PWID should have more support concerning sexual education, and teachers who teach sex education should undergo more training. Learning about the body needs to be concrete, visual, and participatory, and colour codes may help PWIDs take their medication independently (World Bank, 2010).

Policies Regarding PWIDs

In 2006, Zambia took part in the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Due to Zambia's participation in the UNCRPD, they are required 'to raise awareness of disability and combat prejudice and discrimination' (UNHRC, 2016). Zambia has attempted to fulfil this obligation by encompassing these ideals in legislation since the passing of the convention (Sakala & Korpinen, 2013). The Zambian government operates under a dualistic system when it comes to the ratification and domestication of international human rights instruments (Marbesa, 2011). This means that following the cabinet's ratification of international law, Parliament will next domesticate these international instruments into their local laws. The CRPD was first ratified in 2010 and is symbolic of the Zambian government now recognizing that disability should be considered a social justice and human rights issue as opposed to 'objects of charity, medical treatment and social protection' (Marbesa, 2011).

Following the ratification of the CRPD, one of the Zambian government's first attempt at domesticating the ideals of the UN Convention occurred when they passed the Persons with Disabilities Act of 2012, which in-turn repealed the 1996, Persons with Disabilities Act (Sakala & Korpinen, 2013). Despite the government repealing the 1996 disability law, the Zambian Agency for Persons with Disabilities (ZAPD) continued to be used by the Zambian government. The roles of ZAPD include raising awareness and helping to create government advocacy for PWD; they are held accountable for enforcing and advising the ministries on their accordance with the Persons with Disabilities Act, 2012. (Sakala & Korpinen, 2013). Zambia further domesticated the beliefs of CRPD by creating a Disability Focal Point Person (DFPP) within each ministry (Zimba, 2016).

The Zambian government's most recent attempt at domesticating the beliefs of the convention was shown when the government put the Ministry of Community Development, Mother and Child Health (MCDMCH) in-charge of handling National Disability Policy (Sakala & Korpinen, 2013). According to the policy brief on National Disability Policy

created by the MCDMCH, they believe that Zambia can become a disability friendly country by increasing collaboration between DPOs and Ministries and increasing awareness among the Zambian population. (Republic of Zambia, 2015). Despite MCDMCH plans to address the following issues, there have been unilateral movements within the Zambian government, which has resulted in MCDMCH's transformation to Ministry of Community Development and Social Welfare. The Ministry of Community Development and Social Welfare is now responsible for handling people with disabilities (Lungu, 2015). Meanwhile, the Ministry of Health (MoH) is now in-charge of mother and child health and held responsible for implementing HIV/AIDS awareness campaigns, which should include reaching out to PWDs (Lungu, 2015).

In MoH's launched National Health Strategic plan and the National Aids Strategic Framework, PWDs are specifically mentioned as a vulnerable population and target group. However, neither of the frameworks provides information on the specific actions that the government is supposed to take to increase PWDs access and knowledge of SRHR. Both provide general information such as the government will increase support by increasing their budget, mainstreaming of their policies and strengthening the current systems and institutions emplaced for all of their targeted groups (Zimba, 2016).

The Sixth National Development Plan 2011-2015, best encompasses Zambia's goals for PWDs in the near future. Zambia plans to better incorporate PWDs into society by continuing to develop and create pieces of legislation, policies, and programmes that align with CRPD. The goals of the imminent future include: making DPOs more accessible to PWDs, more inclusive education and skill training for all levels of disability, and free medical and healthcare for PWD (Wailuya, 2014). Despite the strides Zambia has taken to protect PWDs there still remains the issue that laws largely only exist on paper and are not enforced (Zimba, 2016).

The United Nations (UN) has recognized progress by the Zambian government in the expansion of the protection framework for persons with disabilities (PWD), including the empowering of the Zambia Agency for Persons with Disabilities (ZAPD), and the efforts to make the social protection framework more inclusive of people with disabilities. However, much progress still needs to be made, particularly for PWID in the country.

Methods

To gather information on the current systems and institutions in place that allow for the access of services and information regarding sexual and reproductive health rights and HIV/AIDS prevention for people with intellectual disabilities, relevant literature was reviewed and semi-structured interviews with stakeholders were conducted in collaboration with the Sani Foundation and the Southern African Institute for Policy and Research (SAIPAR). Journal articles and reports detailing the state of SRHR in relation to disabilities, both in Zambia and globally, provided information for the literature review. The stakeholders interviewed included special education teachers, staff at DPOs and NGOs, a doctor and a health clinic worker, and an official from the Ministry of Education. Stakeholders were contacted through phone or email through contact information found online or through the Sani Foundation, and interviews were performed either in person or over phone. Thirteen interviews were conducted, including representatives from the Zambia Agency for Persons with Disabilities (ZAPD), Special Hope Network (SHN), Zambia Association of Parents for Children with Disabilities (ZAPCD), the Ministry of General Education (MoGE), Anti-AIDS Teacher's Association of Zambia (AATAZ), Planned Parenthood Association of Zambia, and others. A number of questions were selected for each interview from a longer list based on the type of stakeholder being interviewed, and these questions were left open-ended to allow for the direction of the conversation to be flexible. Notes were taken during the interview, and when given permission, they were recorded using a laptop. To protect the anonymity of some interviewees, their names and organisations are not used in the paper. Information obtained from interviewees was organized by topic in the results section, and used to discuss the state of current institutions and structures available in Zambia for PWIDs to learn about their SRHR and HIV/AIDS prevention information, and to make recommendations to better provide PWIDs this information. This qualitative field research was conducted during June and July of 2016 in Lusaka, Zambia.

Results

The accessibility of information on sexual and reproductive health rights and HIV/AIDS for people with intellectual disabilities was assessed through interviews with a number of relevant stakeholders. The information obtained was categorized under awareness, HIV/AIDS and sexual abuse, parents, general education, other educational tools, healthcare, policy, collaboration and communication, and hope for change.

Awareness and Perceptions of IDs

There is minimal general awareness of IDs in Zambia¹. Throughout the interviews we conducted, we often asked professionals about their definitions of ID. The answers varied slightly, but in general their definitions resembled the previously discussed WHO definition. We then asked several of our interviewees about the general public's awareness and perception of intellectual disabilities. The overarching perception confirmed what was presented in our literature review: the perception of IDs is negative, and PWIDs are seen as people who need to be cared for and have decisions made for them². There is the additional belief that society should just help PWID instead of involving them³. These beliefs and stigma stem from the lack of knowledge and understanding about IDs since general education rarely teaches about disabilities⁴. Therefore, according to ZAPD, the general public knows little about IDs and is often misinformed about the nature of IDs. However, some of the people interviewed stated that the perceptions of IDs are improving, at least in Lusaka⁵. The stigma and negative perception persists and is on grander scale in rural areas⁶. This stigma comes into play when looking at the SRHR of PWID. Our interviews confirmed that the belief that PWIDs do not have sexual feelings is common⁷. As representatives from ZAPCD told us, this belief impacts PWIDs access to health education because it is thought that they do not need it.

Sexual Abuse and HIV/AIDS

Several interviewees noted that people with intellectual disabilities are particularly vulnerable to sexual abuse, and by extension HIV/AIDS. One cause of the prevalence of sexual abuse towards PWIDs is the virgin cleansing myth, which was mentioned previously

¹ Personal communication with a representative from UTH Special School.

² Personal communication with a representative from UTH Special School, a representative from ZAPD, and a teacher at Cheshire Home Society.

³ Personal communication with a representative from ZAPD.

⁴ Personal communication with a representative from ZAPD and a representative from ZAPCD.

⁵ Personal communication with a representative from UTH Special School and a teacher at Cheshire Home Society.

⁶ Personal communication with a representative from ZAPCD.

⁷ Personal communication with a representative from UTH Special School, a teacher at Cheshire special school, representatives of the SHN, and a representative from ZAPCD.

in the background information, and is still prominent in Zambia according to the representatives from the SHN. Additionally, others may take advantage of PWIDs, who don't have enough information to prevent the abuse, and this can result in the transmission of HIV/AIDS⁸. For example, an HIV/AIDS specialist at the University Teaching Hospital explained a situation where this occurred. A young boy born with cerebral palsy was sexually abused by his father and a friend of his father, both of whom were HIV positive and intended to cure themselves based on what they understood of the virgin cleansing myth. The boy, who was HIV negative, is now HIV positive as a result of the abuse. As a result of stories like this one, many of the PWIDs who go to clinics, go for treatment following sexual abuse⁹. As we were told by the representative from UTH special school, stigmatisation towards people with HIV/AIDS also exists. Many students with IDs receive HIV/AIDS through mother-to-child transmission, and as a result it is a difficult topic to discuss with parents, as they do not want others to know they have HIV/AIDS¹⁰. However, one teacher from Cheshire Home Society stated that the school she works at is careful never to stigmatise those with HIV/AIDS.

PWIDs and their SRHR

Because the community generally believes that PWIDs do not have sexual needs, they receive little information about the SRHR¹¹. However, our research suggests that informing PWIDs of their SRHR is of critical importance. One of interviewees, Janet Mwanza Kakusa, who mainly works with the hearing impaired, stated that when she interviewed people with disabilities, most of them stated that they had previously engaged in sexual behaviour and that it was their right to do so. Furthermore, she stated that they often saw sexual behaviour as a way to escape from their disabilities. However, when she asked them about what they knew about sex there was quite a gap in knowledge. For example, many thought that one could contract HIV/AIDS through the sharing of cups, clothes, or toilets. Although this research was conducted on those with hearing impairments, she mentioned that several of the learners she interviewed also had intellectual disabilities. Additionally, PWIDs are even more vulnerable to the lack of information due to the strong stigma associated with the ID and the nature of their disabilities. Thus, they may receive less information and understand less about their SRHR.

Most of our interviewees agreed that there was a wide gap in the information PWID were getting and the information that PWID should be getting about their SRHR¹². Moreover, sometimes when information is provided it is misinterpreted leading to incorrect beliefs about sexual health and HIV/AIDS¹³. For example, if a teacher goes over information

⁸ Personal communication with a teacher at Cheshire Home Society and a clinic nurse.

⁹ Personal communication with a clinic nurse.

¹⁰ Personal communication with a representative from UTH Special School.

¹¹ Personal communication with Janet Mwanza Kakusa and a representative from PPAZ.

¹² Personal communication with Janet Mwanza Kakusa and representative from PPAZ.

¹³ Personal communication with a representative from UTH Special School, a representative from ZAPCD, and Janet Mwanza Kakusa.

quickly and says ‘HIV cannot be transmitted by sharing cups’, but the student with an ID misses the word ‘not’, the student may think that HIV can be transmitted by sharing cups. Because of these discrepancies and the vulnerability, all stakeholders contacted felt that it was important to make PWID aware of their SRHR. Since information about sexual health and reproduction comes from many sources, we investigated the efficacy of different sectors of society in providing PWIDs with SRHR information.

Parents and Families

In the Zambian context, sex is a taboo subject between parents and children. According to Zambian Association of Parents for Children with Disabilities, parents and children do not talk about sexual relationships. Instead, to receive information about their sexual health, young people will talk to other relatives such as grandparents, aunts, or uncles¹⁴. Parents of a child with intellectual disabilities feel even less comfortable speaking to their child about their sexual health, often because according to a representative of Teacher Education and Special Services (TESS) within the Ministry of Education and a special education teacher at a primary school, parents are not even aware that a PWID has sexual needs¹⁵. This misinformation starts at birth, as doctors do not give much information to the parents about the ID according to the Special Hope Network. Consequently, representatives of UTH special school and of Zambia Association of Parents for Children with Disabilities (ZAPCD) stated that parents feel helpless and have trouble accepting that the child has an ID. They then turn to traditional thinking and believe that the child is a cursed or is a curse to the family¹⁶. This line of thought often leads to inadequate parental involvement, to neglect, or to parents hiding the PWID¹⁷.

According to the ZAPDC, parents do not have the tools and resources necessary to teach their children about their sexual health. Moreover, culturally parents are not the ones to teach their children about sex and relationships, the role is assigned to grandparents, aunts, and uncles¹⁸. Yet, several stakeholders, such as representatives from SHN and ZAPDC, stated that information about sex should come from the parents because the parents have the closest relationship with the PWID. Thus, it was suggested by some stakeholders, a representative from UTH Special School and a representative from the MoGE that parents should be better trained to talk to their child with an intellectual disability about their SRHR. The representative from MoGE also mentioned that this training should come from NGOs and ministries and that parents who are already trained

¹⁴ Personal Communication with a teacher at Cheshire Homes Society and a representative from the Anti-AIDS Teacher Association of Zambia.

¹⁵ Personal Communication with a representative from the MoGE and a teacher in the special unit of Chibelo Primary School.

¹⁶ Personal Communication with a representative from ZAPCD.

¹⁷ Personal Communication with a representative from UTH special school, from the MoGE, and a teacher at Cheshire Home Society.

¹⁸ Personal Communication with a representative from ZAPCD.

could further other parents through parent support groups existing under organisations like ZAPCD, Sani Foundation, SHN, and other DPOs.

There have been some more general outreach programmes to attempt to involve the parents in the life of the PWID¹⁹. These outreach programmes have been seen as generally helpful. However, the outreach programmes we encountered do not help parents understand the sexual health and needs of the children. As a result, the programmes do not include components that tell parents how to teach their children about sexuality.

Education Sector

If a PWID attends school in Zambia, they are either placed in a special unit at a mainstream school or they attend a school that is specifically for people with disabilities. The Zambian government is in charge some of these special schools while the private sector or NGOs are in charge of others. The special schools run by the government and the special units in mainstream schools both follow the general education curriculum, but it is up to the special education teachers to adapt the curriculum for PWIDs²⁰. Teachers are expected to find the proper materials and resources to teach PWIDs in the way the teacher feels will be the most effective²¹.

The Ministry of Education has put together a Sexual and Reproductive Health Framework. According to the representative from AATAZ, this framework, which includes information about HIV/AIDS, is now integrated in the general curriculum, meaning that students learn about their reproductive health in a variety of classes such as the sciences, social studies, etc. However, there no specific time dedicated to teach sex education in the mainstream programmes. Through our interviews we were able to see that the SRH information disseminated to PWID varies greatly by school. The age at which sex education was first taught and the content taught differed by school and teachers. We saw that this was the case because government requires that a curriculum should be taught but it does not mandate how it should be taught²². Some stakeholders believed that sex education should start as early as possible while others believe it should mainly be taught between the ages of 12 to 15 years old²³. Furthermore, some schools taught abstinence to their students with IDs while others incorporated information about safe sex in the sexual education programmes. In some institutions, the type of information taught also depended on the age of the learner²⁴.

¹⁹ Personal Communication with representative from SHN

²⁰ Personal Communication with a representative from AATAZ

²¹ Personal Communication with a representative from AATAZ

²² Personal communication with a representative from UTH Special School

²³ Personal communication with a representative from UTH Special School, a representative ZAPCD, and a representative from the MoGE

²⁴ Personal Communication with a representative from UTH Special School.

The method and type of information taught to students with IDs was highly dependent on the school. For the purposes of this section, we will keep the identity of each school anonymous. One of the schools interviewed put together a more specific programme to teach PWID about their SRHR. In this programme, experiences are discussed and an answer and question format is used. At another school, the teachers themselves are responsible for adapting the curriculum and teaching the students with IDs about sexual health. At this school, teachers teach about body changes at puberty, pregnancy, and the dangers of unprotected sex. To ensure that all students with IDs understand what is being taught, teachers repeat the information and reinforce it with examples and drawing. Within the special unit of a different school in Lusaka, the teacher we spoke to whom we spoke said she adequately taught her students about their sexual health given the resources she had available. However, she also gave examples of how some of students had been sexually abused. Finally, at a nongovernmental school, there was no set sexual health curriculum. When we asked the why the school did not have a set curriculum for sexual education, they answered that because they focused on younger kids, they did not see SRHR as a priority. Yet, when they saw the need, they informally addressed the topic of love and relationships. Our interviews with a variety of schools demonstrate that range of SRH information given to PWID depending on the school that they attend.

Most stakeholders agreed that the education system and teachers play a crucial role in teaching PWID about their SRHR. However, teachers complained that they were not provided the proper material to teach students about their sexual health²⁵. They stated that they would be better equipped to teach PWID about SRHR if provided with easy read²⁶ material including books, pamphlets, charts, and diagrams. The teachers also mentioned that special units and special schools were understaffed. Since it takes longer to teach PWID, teachers have to spend more time with the students to meet the expectations of the curriculum. Hence, the MoGE and special education teachers agreed that there should be about one teacher per four students. However, in reality we witnessed that in government schools the ratio of teachers to students was about one teacher for every ten students²⁷. Additionally, the high teacher and staff turnover in special education makes it hard to train teacher to teach PWID about their SRHR. Teachers and other interviewees also brought up ideas concerning the training they received. Some stated that the teachers were not specialized or properly trained to teach their students with intellectual disabilities about sexual health²⁸. One of our stakeholders suggested that more research-based methods should be taught to special education teachers and that special education teachers should receive more hands-on training²⁹.

²⁵ Personal communication with representatives from UTH Special School, a teacher at Cheshire Homes Society, and a special education teacher at Chibelo Primary School.

²⁶ Easy read material is material adapted to people with intellectual or learning disabilities. It presents the text in an easy, accessible format. It usually uses short, simple sentences combined with images (Foundation for People with Learning Disabilities).

²⁷ Personal communication with representatives from UTH Special School, a teacher at Cheshire Homes Society, and a special education teacher at Chibelo Primary School.

²⁸ Personal communication with a representative of TESS within the MoGE.

²⁹ Personal communication with representatives of SHN.

Other Educational Tools

Educational programmes offered outside of school curriculums have the potential to provide PWIDs information about their sexual and reproductive health rights and HIV/AIDS, but at this time no organisation we interviewed offers this service. Planned Parenthood Association of Zambia (PPAZ) offers health talks in communities and four clinics that disseminate SRHR and HIV/AIDS information, however PWIDs are not considered to be a vulnerable group due to the lack of information the organisation has on how to provide services to them. As a result, there are no special programmes to target them, not because of a lack of funding but because of this lack of information³⁰. The Anti-AIDS Teachers' Association of Zambia (AATAZ) also provides information on SRHR and HIV/AIDS, but PWIDs are not specifically reached through this programme. The association offers programmes at 66 schools in Lusaka to provide this information; however, a lack of resources, particularly financial and time resources, prevents them from creating programmes specifically for PWIDs³¹. Finally, the Special Hope Network, an NGO that works with children with disabilities, does have outreach programmes that work with children with IDs and their parents. These programmes are offered at compounds, and parents and PWIDs in the area attend for six hours each week. However, this programme does not teach information on SRHR and HIV/AIDS, although it is specialised for PWIDs³². Across these three different programmes, none are able to teach SRH and HIV/AIDS information to PWIDs, showing there is a lack of other educational tools and programmes to meet this need.

Healthcare Sector

Healthcare can play a role in preventing IDs, as many causes of the prevailing IDs in Zambia are preventable, and for those who already have IDs, early identification is important³³. Issues that occur before, during, or after birth, including prolonged birthing process or an untreated illness, can cause IDs³⁴. Currently in Zambia, there is no screening process at birth to identify children with IDs. One achievable solution to this issue is to follow the model used in Zimbabwe for recognizing children with IDs. Infants who are at risk for IDs at birth have an indication of this on their records, then at a follow up appointment they are screened for an ID. This process has been highly effective in Zimbabwe, and could be very beneficial to use in Zambia³⁵. Children in Zambia who are diagnosed with an ID receive this assessment at a hospital; however, this service is only available at three hospitals in the

³⁰ Personal communication with a representative of PPAZ.

³¹ Personal communication with a representative of AATAZ.

³² Personal communication with representatives of SHN.

³³ Personal communication with representatives of SHN.

³⁴ Personal communication with representatives of SHN.

³⁵ Personal communication with representatives of SHN.

country, all of which are located in Lusaka. This assessment is then used by a specialist then uses to assign them to a school³⁶.

There are a number of issues that healthcare workers face in providing treatment to PWIDs. Although health clinics and hospitals should be providing information on sexual health according to the one of the teachers we interviewed, healthcare workers are not given enough training on how to treat PWIDs and present information to them in a way that they can understand, including information on sexual health³⁷. There are also no nurses specialised to treat PWIDs³⁸. The tools and resources developed to teach PWIDs are only accessible to people at some hospitals and schools, not the wider population³⁹. For example schools associated with medical facilities have advantages over those who are not⁴⁰. Additionally, while some facilities like UTH are equipped to present information to PWIDs, clinics often do not have the tools and resources to do this⁴¹. Furthermore, while every constituency has a government clinic, these clinics are understaffed, under resourced, and there is not much knowledge about disability as a whole⁴². Despite the prevalence of these issues, DPOs have not reached out to one health clinic interviewed⁴³. One vision for change offered by an HIV/AIDS specialist interviewed at UTH is the advanced treatment centre model. These centres link the community and education sectors to the healthcare sector, because of the impact they have on healthcare⁴⁴. Furthermore, it would be beneficial to have more schools with relationships with healthcare facilities to better provide students with health services and information⁴⁵. Finally, there should be clinics and services specifically for PWIDs, with nurses who are trained to identify and treat PWIDs⁴⁶.

For PWIDs and parents, there are a number of barriers in accessing and utilizing treatment. Due to the stigma associated with IDs, many parents are reluctant to even bring their child to a healthcare worker⁴⁷, and knowledge on what services are available at clinics is not given to PWIDs also due to stigma⁴⁸. At one healthcare clinic in Lusaka, a nurse interviewed said that she had not seen patients with IDs come in for information regarding their SRHR, because they don't have knowledge on what services the clinics offer, nor do their parents, but this needs to change. When PWIDs do go to clinics with their parents, healthcare workers typically explain the information to the parent, with little effort to ensure that the

³⁶ Personal communication with a representative of UTH special school.

³⁷ Personal communication with a HIV/AIDS specialist at UTH, representatives of SHN, representatives of ZAPCD, Janet Mwansa Kakusa, and a clinic nurse.

³⁸ Personal communication with representatives of ZAPCD and a clinic nurse.

³⁹ Personal communication with a HIV/AIDS specialist at UTH.

⁴⁰ Personal communication with a clinic nurse.

⁴¹ Personal communication with a clinic nurse.

⁴² Personal communication with representatives of SHN and a clinic nurse.

⁴³ Personal communication with a clinic nurse.

⁴⁴ Personal communication with a HIV/AIDS specialist at UTH.

⁴⁵ Personal communication with a clinic nurse.

⁴⁶ Personal communication with a clinic nurse.

⁴⁷ Personal communication with a HIV/AIDS specialist at UTH.

⁴⁸ Personal communication with a clinic nurse.

patient also understands⁴⁹. There are also barriers that PWIDs face associated with following a treatment regimen. Either the PWID must depend on others to adhere to the regimen, or if they are independent, they may struggle to follow it⁵⁰. Furthermore, some antiretroviral treatments must be taken with food, and many PWIDs struggle with food insecurity, and therefore cannot adhere to the treatment⁵¹. However, for PWIDs at UTH, there is access to school, counselling, specific healthcare workers, and upkeep⁵².

Policy

When evaluating the results of the interviews, a valid conclusion drawn is that there is a division between policymakers and the people impacted by policies. All of the people interviewed, besides one individual, felt that there are gaps between policy and what actually happens in a classroom. The one individual that felt no gaps currently exist, has never taught students with intellectual disabilities nor have they interacted with PWIDs on a daily basis, so their opinion comes from a different perspective. The individual believed no gaps existed because all teachers receive the same amount of attention from government and they all have the same resources provided to them by the government.⁵³ The rest of the interviewees believed that the reason for the gap between policy and implementation could be linked to policy makers not being aware of PWIDs needs. Specifically, we are addressing the gaps that exist when government is implementing Divisions 1 and 2 of the Persons with Disabilities Act, which are based off of the 24th and 25th Articles of the UNCRPD. A general census among the interviewees was that special education teachers should be better incorporated into positions of power such as Ministry or school government positions to close the existing gaps between policy and practice.

A contributing reason to the gaps between policy and practice is the heavy reliance upon ZAPD, the key organisation behind implementing the Persons with Disabilities Act of 2012. The representative from ZAPD stated that their failure to properly implement policy was due to two factors: lack of funding and human resources. The representative of ZAPD felt that government does not provide them with enough funding to be able to properly support disability initiatives. The human resource problem is a result of not enough people knowing about the struggles that PWDs endure. The people that are involved in the disability movement are usually only involved because one of their family members has a disability.⁵⁴ The representative believed that ZAPD could obtain better funding if there was greater awareness of PWDs. The lack of sensitivity towards PWDs is demonstrated by the fact that neither government policies nor the books used in schools are written in a way that is understandable to PWID.

⁴⁹ Personal communication with a HIV/AIDS specialist and a clinic nurse.

⁵⁰ Personal communication with a HIV/AIDS specialist at UTH.

⁵¹ Personal communication with a representative of AATAZ.

⁵² Personal communication with a representative of UTH special school.

⁵³ Personal communication with a representative of AATAZ.

⁵⁴ Personal communication with a representative of ZAPD.

A department of the Ministry that was interviewed was TESS (Teacher Education and Specialised Services), which is responsible for overseeing how special education is taught in the school systems. When questioning the Head of TESS about how to improve PWIDs access to their SRHR, he stated that policy should be improved because under the current system all students receive the same funding. However, according to Article 22(2)(f) under Division 1 of the Persons With Disabilities Act, schools are supposed provide resources that maximise a student's possible academic and social development. The MoGE gives funding for these resources to the schools, meaning the government covers the costs of these additional learning materials. Under this provision, it would seem that schools should have funding allocated to making sure adequate resources are available to students with disabilities; however, this information would contradict statements made by the head of TESS.

As previously mentioned, the nurse that was interviewed felt that PWIDs rarely use clinics. Additionally, the nurse felt that fellow nurses, including herself, were not adequately equipped with tools nor was she specifically trained to provide services to a PWID. The statements made by the nurse conflict with Article 27(a) under Division 2 of the Persons with Disabilities Act, which requires that the MoH make sure all facilities are able to provide PWIDs health services within the same range, quality, and charges as non-disabled persons.

Collaboration and Communication

A common issue mentioned by the schools' administrative staff is the lack of weight given to their opinions by the ministry officials. All of the school officials that were interviewed complained about the communication between special education and ministry officials.⁵⁵ Overall, they all believed that communication between the two groups needed to improve. According to a teacher in special education, the only way that government heard of teacher's complaints in the past was from scattered conferences, but there was still no way of making sure their needs are going to be met⁵⁶. None of the teachers interviewed mentioned the existence of other platforms that can be used to voice their opinions to government. All of the schools that were interviewed stated that a member of the Ministry had not visited their school within the last year. Out of the 646 schools in Lusaka, the MoGE, the ministry responsible for inspecting the sexual education taught in schools, had only visited 64 schools.⁵⁷ The reason they were unable to visit more schools is because they have a limited amount of time and resources⁵⁸.

⁵⁵ Personal communication with a teachers at Bauleni School, UTH Special School, Chibelo Primary School and Cheshire Special School.

⁵⁶ Personal communication with a teacher at Bauleni School.

⁵⁷ Personal communication with a representative of AATAZ.

⁵⁸ Personal Communication with Janet Mwansa Kakusa.

Among the representatives that were interviewed, all of them were consistent in stating that there needs to be greater communication and collaboration among the different organisations that help PWIDs. All of the representatives were asked who were the key stakeholders and all of the representatives at least replied that: parents, special education teachers, DPOs, government officials, and health clinics were the people that should be in regular contact.

The lack of communication between special education and governmental figures has affected the way teachers teach sex education to students in special education. Based off the Zambian Education Bill, there is no separate curriculum for students without disabilities and students with disabilities. Some of the teachers interviewed felt that a separate curriculum is not ideal because students with disabilities need to still learn the same material and receive a similar quality education. However, the information presented to students with disabilities is left up to the teacher's discretion. The representative from PPAZ shared that government's leniency in endorsing curriculum has resulted in not all the same information being provided to all students. The representative from PPAZ noted that during their trips to different schools they noticed some endorsed abstinence while others endorsed safe sex.

Among the individuals that were being interviewed, most of them felt that DPOs currently do not play a role in the education system.⁵⁹ One of the teachers stated how she did not know of a continuing education programme, where she could send a student if she felt they were not prepared to go into the mainstream education system. Many of the interviewed teachers said they would like DPOs come to their schools and have them articulate what they feel PWIDs should know about their SRHR. Previously, the Bauleni School had great relations with the ZAPCD, but their last meeting with the school took place in 2010.⁶⁰ When interviewing the representative for PPAZ (Planned Parenthood Association of Zambia) he stated that currently, PPAZ has no programmes or specialty training for persons with disabilities. They said that the reason that they did not have any initiatives for PWIDs was not due to funding issues but because they did not consider PWIDs a vulnerable population. Near of the end of the interview he said moving forward he would be open to working with a DPO if they had been approached.

There has been strong collaboration between schools that are either attached to a hospital or in close proximity to a clinic.⁶¹ A representative of the hospital acknowledged that they should visit other schools, but their efforts remain limited due to their resources⁶². The Head Teacher of the Bauleni Special School has collaborated with the local clinic to host health talks throughout the school year.

⁵⁹ Personal communication with a teachers at Bauleni School, UTH Special School, Chibelo Primary School and Cheshire Special School.

⁶⁰ Personal communication with a teacher at Bauleni School.

⁶¹ Personal communication with a teachers at Bauleni School and UTH Special School

⁶² Personal communication with a HIV/AIDS specialist at UTH

Change

The trend for people who have constant interaction with PWIDs shows that they are more hopeful that change can take place.⁶³ While some of the people interviewed feel that the stigma associated with PWIDs exercising their SRHR has decreased over time, many still feel it is a barrier to change. The stigma still exists because PWD are not regularly seen in their communities⁶⁴. It is hard for the people of Zambia to identify a person with an intellectual disability because they do not know how to define them. One representative felt that people in Zambia could not identify a person with an intellectual disability, but if you said a mentally retarded person then they would be able to identify them⁶⁵. In order to increase awareness many of the representative believed different vehicles could be used such as radio and television.

Despite the representatives of the Special Hope Network (the only non-Zambian people interviewed) feeling that there is a clear chain of command when it comes to creating change in Zambia, the results from the interviews indicate otherwise. When speaking with organisations associated with the government, they believed that in order to change how government approaches the disability movement, there needs to be greater advocacy by the constituents of Zambia. The representative of ZAPD believed that collaboration could start once people began to advocate for change. Additionally, the representative from ZAPD believed that they possessed persuasive power as an entity of the government, but their actions do not gain traction if people are not advocating for the change. While the non-governmental figures believed that change could only take place when it starts from the top and filters down.⁶⁶ This demonstrates while many believe change can happen in Zambia, there is no clear consensus on how it starts.

⁶³ Personal communication with a teachers at Bauleni School, UTH Special School, Chibelo Primary School and Cheshire Special School.

⁶⁴ Personal communication with representatives of SHN.

⁶⁵ Personal communication with a representative of ZAPD.

⁶⁶ Personal communication with a teachers at Bauleni School, UTH Special School, Chibelo Primary School and Cheshire Special School and HIV/AIDS Specialist at UTH.

Recommendations

In light of our results, we suggest changes in several sectors to increase PWIDs' awareness of their own SRHR. All of these recommendations will have a greater impact if there is an increase in awareness and a destigmatisation of IDs.

Recommendation for Parents and Families: Destigmatisation of IDs and SRHR within the Family Context

In light of cultural barriers, parents should not be relied on to talk about sexual health with their children. However, within the context of disabilities, it may be beneficial for parents to open that conversation with their child with an ID. In order to do so, parents should be provided with training by DPOs as to how to best approach the conversation. We also recommend that parents come into the sex education classes of PWIDs to see what the PWIDs are learning. The parents would then be able to reinforce or complement the information at home.

Parents should also become advocates for the rights of their children with disabilities. Because PWIDs have trouble advocating for themselves, parents should be at the forefront of the awareness and destigmatisation movement. There should be capacity building workshops at the community level by organisations such as ZAPCD to empower parents to advocate for their child with an ID.

Recommendation for the Education Sector: Adapting the Curriculum, Increasing the Training of Teachers, and Providing Better Tools for Teachers

Because of the great variation between the sex education curriculum taught between different schools for PWID, we recommend that special education teachers and curriculum developers work together to better and more uniformly adapt the sex and health curriculum for PWID. In this adaptation, curriculum developers and special education teachers should decide at what age to start the sex education and what should be included for each age group. From our research, we recommend that health education start as early as possible due to the increased vulnerability of PWID to sexual abuse. We also suggest that the curriculum involve a list of tangible goals that the PWID can learn to reach. For example, by a certain age PWID should know what is or is not an acceptable touch by another person.

Along with adapting the curriculum, it would be beneficial to better train teachers to inform students about their SRHR, as several interviewed teachers said they felt like they had not received adequate training to teach about SRHR to PWID. For example, one of our stakeholders suggested that special education teachers receive more hands-on training.

More hands-on teaching could be achieved through involving soon-to-be special education in special education classes. Along with better-trained teachers, there should be more teachers per student with ID in classes. The student to teacher ratio should be about four or five students per one teacher as recommended by most of our stakeholders.

Even with better training of special education teacher and student to teacher ratio, the Ministry of Education should provide teachers with more tools and resources to teach sex education. Specialists should develop books and posters in easy-read format to distribute to special education schools. When provided with these materials, teachers would be able to reinforce SRHR topics covered in the classroom. Videos and drama skits could also help reinforce the material.

Under the current system, special education is only represented on a ministry level through the position of TESS. Special education is one of four units TESS oversees. According to statistics provided by the MoGE, there are 108,149 students with special needs as of 2014 (nearly 3% of the students that are attending school). Based on the handful of teachers that were interviewed, many of the special education teachers interviewed believed that the issues of PWIDs were not being addressed because members of the ministry do not understand their needs⁶⁷. Additionally, when speaking with the Head of TESS about the gaps in policy, the suggestion he made contradicted current policy. Thus in the short term, we recommend that TESS increase the amount of time they spend advocating and catering to the special education population. Based off the interview, we believe that TESS should have a greater understanding of what happens in the classroom.

Then, ideally in the long-term and with enough resources, we recommend that there be greater representation of disability specialists in ministry positions. For instance, in the MoGE there should be some ministry positions filled with disability specialists, who have experience in special education. We believe that greater representation in government will help make sure students with special needs are not forgotten and that resources are better allocated.

Recommendations for Health Sector: Greater Involvement in Informing PWID of their SRHR

Currently, most of the information PWIDs receive about their SRHR comes from family members or the education sector. However because the information received is still sparse, greater involvement of the health sector would enhance the information PWIDs receive about their sexual health.

⁶⁷ Personal communication with a teacher at Bauleni School, UTH Special School, Chibelo Primary School and Cheshire Special School.

First, early identification of PWIDs should become standard practice. A system should be developed that is similar to the one used in Zimbabwe, as previously described in the results section. Early identification will allow parents to learn earlier about their child's ID, and data could be collected to better estimate the prevalence of IDs in Zambia. Furthermore, healthcare workers should receive more training concerning how to convey information to PWIDs; healthcare workers should be able to explain SRHR and HIV/AIDS information to PWIDs, and they should be able to recognise when PWID have been sexually abused. Additionally, the myth that PWIDs are asexual should be debunked to enforce healthcare workers to provide PWIDs information regarding their SRHR. All healthcare workers should either have a basic understanding of how to do this or there should be at least one highly trained health worker at each facility whose responsibility is to inform PWID. One of our stakeholders even suggested specific clinics for PWD. In these clinics, the stigma regarding disabilities would be decreased and consequently, PWID may be more likely to visit these clinics. Furthermore, having healthcare workers trained to treat PWIDs can decrease the need for a third person to attend appointments with the patient. By having only the healthcare worker and the patient in the room confidentiality is improved, which is important because the current lack of confidentiality discourages PWIDs from attending clinics.

Resources to provide information about SRHR and HIV/AIDS, such as pamphlets, should be provided at clinics in an easy read format. This will allow PWIDs, particularly those who are no longer in school to receive information on their SRHR. Furthermore, because PWIDs are more susceptible to HIV/AIDS but may have difficulties in adhering to treatment regimens, resources to aid in this should be provided. This can include calendars, pamphlets, and colour coded pill containers designed to specifically help PWIDs follow HIV/AIDS treatment regimens.

We also recommend that the healthcare sector sponsor more outreach events. For example, specialized nurses should visit special units in school to teach PWIDs about their health. Nurses could also visit constituencies within Lusaka and give presentations about the health of PWDs.

Increased Collaboration Between Organisations

Moving forward, there needs to be greater communication among stakeholders within the disability movement because, currently, the disability movement lacks cohesion. If entities of the government, international NGOs, DPOs, and parents work together, they can tackle more issues. According to the SNDP, the Zambian government is working on initiatives such free healthcare and accessibility to buildings and facilities, which are things PWDs need. However, if PWDs are not receiving the proper information on how to access health services and schools do not have the correct learning materials, these initiatives are not very useful. Additionally, if a large percentage of children with disabilities are not going to school, these initiatives are not helping them. By having key stakeholders agree on a vision,

they can focus on pooling resources to solve the most relevant issues first and eventually, they can move on to solving other issues that PWIDs encounter when trying to access their SRHR.

A critical obstacle hindering collaboration among different stakeholders is the lack of awareness of PWID among NGOs concerned with SRH. For example, PPAZ had never thought of PWID as a vulnerable group, but if a DPO brought this idea to their attention, they may be more willing to fund programmes for PWID. In other words, DPOs need to approach NGOs that have more resources so that they can collaborate to target PWID. To facilitate better bonds between DPOs and schools, the current, compiled list of DPOs should be distributed to teaching facilities and/or posted on the ZAPD website. With this list on hands, teachers could recommend organisations, such as the Sani Foundation, for a PWID seeking further education. We also recommend that a special education teacher organisation is formed, so there is greater communication among teachers involved in special education. Special education teachers will use this organisation, so they can share their grievances and teaching methods that have been successful in the classroom. In addition, this organisation would be main source of communication between the ministries and special education faculty.

National awareness days should also be used as a method to bring awareness and advocate for PWID. According to the Ministry of Community Development and Social Welfare's policy brief, they already have plans of implementing national awareness days such as National AIDS Day, National Women's Day, and the International Day of Disabilities. To ensure that these national awareness days do not go unnoticed, DPOs need to visit local schools and host health talks. For instance the national Day of Disabilities, DPOs need to go into schools and provide mainstream students with correct information about disabilities. By informing the mainstream students about the myths and misconceptions that exist in Zambian culture, it will help decrease the stigma associated with PWIDs when they are accessing their SRHR. Additionally, on International Disability Day and National AIDS day, DPOs could visit special education units and teach PWIDs about self-advocacy and how PWIDs can access their SRHRs.

Conclusion

Through our research, we have established that the current systems and institutions in place do not adequately provide PWID with knowledge of their SRHR. Although the education system provides some opportunities for PWID to learn about their SRHR through sex education classes, the health sector, and families provide little to no ways for PWID to learn about their SRHRs. In order to expand the role of each of these sectors and to promote change we have put together a proposed model for change. This logic model is presented in Appendix I. Given the previously proposed recommendations, we outlined the actions and players necessary to reach short, medium-term goals, as well as to eventually reach the long-term goals of decreasing HIV/AIDS and sexual abuse incidence for PWID in Zambia.

Our inputs to the model include funding, staff, research, and time. Using these inputs, activities could be implemented such as: outreach programmes, better cooperation between schools and clinics, the creation of books and posters to teach PWID about their SRHR, better training of special education teachers, etc. These activities would reach important stakeholders and players that would need to be involved to achieve the short, medium, and long-term goals. This logic model also includes external factors and assumptions, the most critical ones being the stigma and lack of awareness regarding IDs, and the lack of financial resources from the Zambian government. Thus, in order to create change these barriers need to be addressed. Realistically, the lack of financial resources cannot be easily changed. To compensate, DPOs and NGOs concerned with SRH need to utilise existing resources and can work on decreasing stigma and discrimination, as most of our outlined recommendations cannot be carried out if the general population does not see the vulnerability of PWID.

Several factors make Zambia unique in regards to this topic. First, the cultural taboo that prevents parents from talking with their children about sex has removed one important method of learning about SRHR for PWIDs from an already limited number of options. Furthermore, the policies currently being used to protect PWIDs are not being implemented in ways that suit the needs of the Zambian population. The Persons with Disabilities Act of 2012 is the main piece of legislation protecting PWDs and it follows the guidelines set in the CRPD by being nearly an exact replica of the guidelines. The CRPD was meant for participating countries to raise awareness of disabilities, and now Zambia must adjust the guidelines to overcome the barriers that exist in the country. Additionally, under Article 33 of CRPD government does not act alone when they want to create change in the disability movement. Civil society organisations, PWDs, and the organisations that represent them all have a responsibility to take on the roles of monitoring how their government follows CRPD, and then voice when their needs are not being met.

Additionally, when the Zambian government ratified and domesticated CRPD, they agreed to Article 8 of CRPD. Article 8 of CRPD states that governments are held responsible for

raising awareness in appropriate, effective, and immediate measures. In order to achieve greater awareness, more research needs to be conducted to evaluate the needs of PWIDs. Accurate statistics should be gathered about the number of PWIDs in Zambia and the prevalence of HIV/AIDS and sexual abuse among this population. Although we suspect that these numbers would be higher than average because of anecdotal evidence, the statistics would serve to prove our assumptions. The statistics could then be taken up to ministries to demonstrate the vulnerability of PWIDs and the need for better SRHR awareness among PWIDs. More research should also be conducted on what PWID actually know about their SRHR, as this was one of the major limitations of our study. Similarly, parents should be interviewed to accurately gauge how much they know or are able to teach their child with an ID about SRHR. With this research in mind, institutions and systems could bridge the specific gaps between what PWID know and what they should know about their SRHR to eventually decrease the incidence and prevalence of sexual abuse and HIV/AIDS in this target population.

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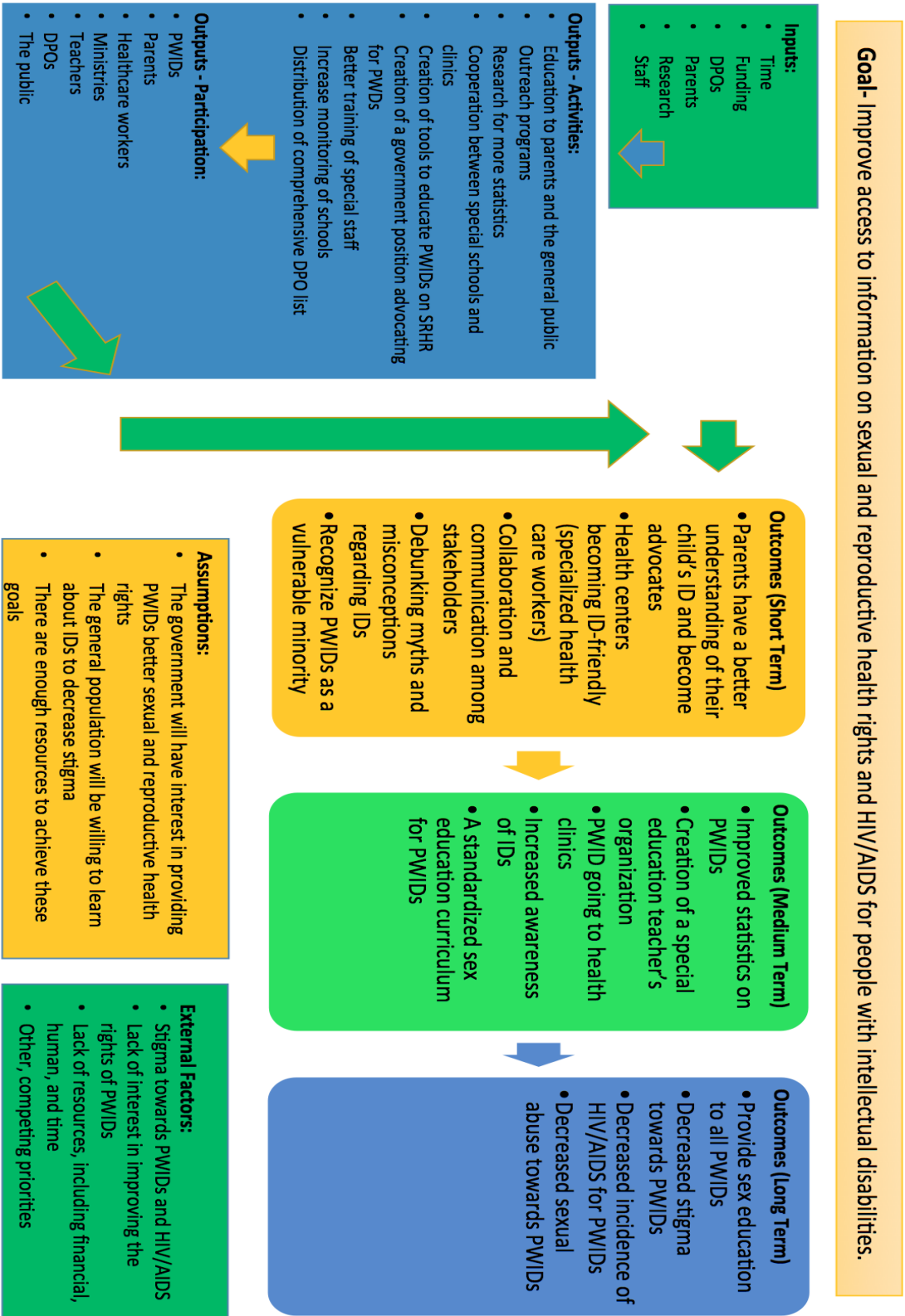
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Appendix A: Logic Model



Appendix B: Limitations

Although we were able to gather information about the current systems and institutions in place for PWIDs to access information about their SRHRs, our research does face limitations. Because of our lack of ethical and Institutional Review Board (IRB) clearance, we were unable to interview PWIDs and parents of PWIDs. Even if some of the stakeholders interviewed were parent to a child with an ID, we were only able to interview them in their professional capacity. Because of this reality we were unable to assess how much information PWIDs actually know. Furthermore, we were unable to gather a parent's opinion of the role they currently for their child with an ID when the child attempts to access their SRHR. However, from the interviews we did conduct we were able to see what resources are currently available and how often they are being used by a PWID. Additionally, we were able to gather information about how teachers and healthcare professionals felt the SRH information provided was being received by PWIDs.

Due to our limited time and resources, we were only able to conduct interviews that were based in Lusaka, the capital city of Zambia. If we had additional time we would've conducted interviews in other cities and rural areas of Zambia. Due to our interviews being based in Lusaka, we relied on statements from our stakeholders to assess how PWIDs access information regarding their SRH in areas outside of Lusaka.

Lastly, our limited time in Zambia only allowed us to conduct 13 interviews. If we had more time in Zambia we would have taken the time to interview more stakeholders and gain a deeper understanding of the current system and institutions being used by PWIDs when they access their SRHR and HIV/AIDS awareness. Based off the questions asked to interviewees, we were able to receive generalised information on the role of each of the stakeholders play.