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Balancing Parent Support with Limited Resources: A Study of Community-Based Initiatives to Support Parents of Children with Intellectual Disabilities in Zambia

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Abstract

Parents of children with intellectual disabilities (CWID) in Zambia lack the necessary support to care for their children. Negative cultural beliefs surrounding disability lead to the discrimination and isolation of parents and their children by the community and their families. Parents of CWID are much more likely to be in poverty than their counterparts with typically developing children. Formal social services for CWID are almost non-existent and many parents are unable to access health-related services for their children. Despite the protection of the rights of persons with disabilities (PWD) in Zambian law, their rights are frequently violated, with parents often unaware that those rights exist in the first place. CWID are denied access to quality education due to the limited number of special education schools and the poor implementation of inclusive education policies. Ultimately, the lack of accessible services places a heavy burden on parents' ability to facilitate their child's growth and development.

The purpose of this research was to identify and analyze the barriers parents face in caring for their children, and the different existing and potential interventions available to support them in a resource-limited, highly-stigmatized context. We accomplished this by conducting a literature review and interviewing representatives from organizations that work with parents of CWID in different African countries, as well as experts in the field of intellectual disability (ID) in Zambia. We found that parents face significant barriers to supporting their children and themselves. However, there are a number of existing interventions being successfully implemented, including parent support groups (PSGs), economic empowerment programs, inclusion initiatives, parent training, and advocacy work. Our interviewees also revealed some of the challenges associated with implementing these programs, such as a lack of funding and the difficulties of managing parental expectations. From these results, we devised a number of recommendations for how parent support can be strengthened through the expansion of existing initiatives or the creation of new ones.

Acronyms

BSNP	Bauleni Special Needs Project
CHSZ	Cheshire Homes Society of Zambia
CWID	Child with Intellectual Disabilities
DPO	Disabled Persons’ Organization
ENAID	Ethiopian National Association on Intellectual Disabilities
ID	Intellectual Disabilities
NGO	Non-Governmental Organization
PODCAM	Parents of Disabled Children Association of Malawi
PSG	Parent Support Group
PWD	Persons with Disabilities
PWID	Persons with Intellectual Disabilities
SAIPAR	Southern African Institute for Policy and Research
SHN	Special Hope Network
UNZA	The University of Zambia
UPPID	Uganda Parents of Persons with Intellectual Disabilities
ZACALD	Zambia Association for Children and Adults with Learning Disabilities
ZAFOD	Zambia Federation of Disability Organizations
ZAPD	Zambia Agency for Persons with Disabilities
ZAPCD	Zambia Association for Parents for Children with Disabilities
ZPHCA	Zimbabwe Parents of Handicapped Children Association

Introduction

Parents of CWID in Zambia face significant challenges in caring for their children. There is intense cultural stigma that surrounds ID, with many people believing it to be a curse (Mung'omba, 2008). Many mothers are frequently abandoned by their husbands and shunned by their communities as a result of these negative attitudes (McNally & Mannan, 2013; Hansen, Siame, & van der Veen, 2014), which interferes with access to adequate education and healthcare-related services for their children (Chitoyo & Muwana, 2008; Nkhosi & Mennon, 2015). While the Zambian government acknowledges that children have a right to inclusive education, it is rarely implemented effectively on the ground (Serpell & Jere-Folotiya, 2011).

The lack of support, coupled with the stigma and high levels of poverty amongst families who have CWID, creates an environment where parents are unable to provide optimal care for their children.

This paper seeks to identify the challenges that parents of CWID face and how disabled persons organizations (DPOs) and service providers can best support them in caring for their children in a resource-limited, highly stigmatized context. After conducting an extensive literature review on ID in Zambia and various forms of parental support, we found that although parents of CWID face a lot of challenges, there is very little existing research on parental support in Zambia, or in Africa more broadly. Therefore, we conducted interviews with a number of DPOs and service providers who work with parents of CWID in order to gain a more comprehensive understanding of current and potential projects to support parents. Since there are a limited number of organizations doing this work in Zambia, we ultimately chose to broaden our study to organizations operating in different countries in Africa. We hoped that by doing this, we could gain a more comprehensive understanding of parent support initiatives that would be applicable to the Zambian context.

Through our literature review and stakeholder interviews, we found that there are a number of different interventions currently being implemented throughout Zambia and Africa as a whole in order to support parents in caring for CWID. PSGs, parent training, and economic empowerment programs were some of the most common forms of support offered. The stakeholders we interviewed offered a variety of perspectives, outlining effective interventions and remaining barriers. We synthesized and analyzed these different perspectives and approaches in our findings section. This paper will be structured as follows: we will first summarize the existing literature that we reviewed and describe the methodology we used to conduct this research. Then we will present our findings from our stakeholder interviews. Finally, we will conclude by providing some recommendations for DPOs and service providers looking to better support parents, while also acknowledging the limitations of our research.

Literature Review

Background on ID

According to the World Health Organization estimates, about 2 million women and men in Zambia, or 15 percent of the population, have a disability (Sakala & Korpinen, 2013). Beyond physical challenges, PWD struggle with social inequality and discrimination from a variety of opportunities and resources. Furthermore, persons with intellectual disabilities (PWID) are especially disadvantaged in Zambia due to the intense cultural stigma, lack of political and societal awareness, and the high cost of care. An intellectual disability is defined by the American Association on Intellectual and Developmental Disabilities (n.d.) as "a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills."

Traditionally, disability has been defined by the medical model, which characterizes disability as "physiological pathologies located within individuals" (Longmore, 2009). In this model, disability is defined by an individual's impairment and requires medical intervention in order to 'solve' the problem. However, the modern disability movement and field of disability studies follow the social model, which argues that "it [i]s not impairment that [i]s the main cause of the social exclusion of disabled people but the way society respond[s] to people with impairments" (Oliver, 2004). According to this social model perspective, these societal barriers must be removed in order to facilitate the full inclusion of PWD in everyday life. This paper will operate under a social model framework, focusing on the disabling barriers that exist within Zambian society, preventing the full inclusion of PWID and their families into the mainstream.

Cultural Attitudes

In Zambia, traditional beliefs and religious views shape the community's perspectives and attitudes towards ID. Disabilities are thought to be caused by "divine retribution or witchcraft" (Mung'omba, 2008), and parents of CWID are punished with a cursed child (Special Hope Network (SHN), n.d.). Due to these negative attitudes towards ID, children are hidden away and restricted access to services like medical care and education in order to avoid public embarrassment and shame (Mckenzie, McConkey, & Adnams, 2013). Because of this restricted access, the children not only cannot seek supportive services, but they are also unable to exercise their basic human rights. Consequently, there is a lack of awareness and fundamental understanding of ID in the community, facilitating ongoing stigma and discrimination (Mung'omba, 2008). Overall, such attitudes prevent PWID from being included and accepted by their families and society at large (Chirwa, n.d.).

Disability and Poverty

A majority of Zambians with disabilities live in poverty (Sakala & Korpinen, 2013). The concept of disability and poverty is multidimensional in that it affects diverse sectors of daily life, including access to necessities, services, and opportunities. Furthermore, disability and poverty are reciprocal; poverty worsens disability by limiting access to the basic services needed while attitudes towards disability worsen poverty by hindering efforts to escape the cycle (Gona, Mung'ala-Odera, Newton, & Hartley, 2010). While ID is already highly stigmatized, living in poverty amplifies the negative perceptions the community has because the poverty-related stigma become coupled with the stigma related to ID. As a result, PWID are pushed deeper into stigma and discrimination, and even deeper into poverty (Filmer, 2005). Along with the barriers that cultural stigma imposes on PWID, other institutional and environmental barriers contribute to their social exclusion, preventing these individuals from pursuing certain opportunities that foster growth and self-sufficiency. Paired with the difficult financial circumstances, families are reluctant to seek appropriate healthcare nor provide sufficient nutrition, which ultimately exacerbates the child's ID (Yeo, 2003).

In addition to medical services, families of a lower socioeconomic status are unable to afford schooling for children with ID (Chirwa, n.d.). According to the African Child Policy Forum (2011), children with ID are the most likely of all disabled children to be out of school, and according to Groce, Kett, Lang, and Trani (2011), only 31.3% of children with intellectual and mental health disabilities attend school. Unable to access the opportunities, like education, that are essential to participating in contemporary society, CWID are at an increased risk of becoming more disadvantaged (Banda-Chalwe, 2012). Ultimately, it can be observed that poverty "increase[s] stigma and discrimination against disabled people, leading to inequality and decreased opportunities to access services and facilities," according to Filmer (as cited by Banda-Chalwe, 2012).

Limitations due to ID

In addition to their restricted access to necessary services and opportunities, PWID are disadvantaged in a variety of other ways overall due to their mere characterization as "disabled". In a comprehensive report, Drew et al. (2011) outlines the various human rights violations and disadvantages PWID face. In the report, it was found that PWID have no social security benefits and no health insurance. While parents play a significant role in supporting and advocating for their children, they also have control over making decisions on behalf of their children in terms of "where and with whom they should live, how their money, property, and personal affairs should be managed, and other aspects of their daily lives" (Drew et al., 2011). With this lack of autonomy, PWID are unable to exercise their right to personal freedom.

Existing Legislation Related to PWID

General Policies

It is important to discuss the strengths and weaknesses of current Zambian policy towards PWID in order to understand the context under which parents operate. Areas where public services or legal protection is lacking become an added burden for the parents as they struggle to ensure their children access the same services and enjoy the same rights as any other child. The Zambian government has instituted a number of laws and policies protecting the rights of PWD. In 2010, Zambia ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Two years later, Zambia domesticated the UNCRPD by passing the Persons with Disabilities Act of 2012 (Sakala & Korpinen, 2013). This act established the Zambian Agency for Persons with Disabilities (ZAPD), which is responsible for coordinating services for PWD, advising the Ministry of Community Development on disability policy, and ensuring the full inclusion and equality of PWD in Zambian society (ZAPD, n.d.).

Education

Outside of the general framework of disability legislation, the Zambian government also has a number of policies relating to the provision of special and inclusive education. The Ministry of Education in Zambia took on the responsibility of providing special education in 1977, building a few institutions and special education schools. Despite these initiatives, there are some challenges when it comes to providing special education access across the entire country. Zambia has a special education teacher's college, the Zambia Institute for Special Education (ZAMISE), which produces a large number of highly qualified special education teachers. However, a majority of special education classrooms and schools are also concentrated in the more urbanized Lusaka and Copperbelt provinces, leaving children with disabilities underserved in the other more rural provinces (Serpell & Jere-Folotiya, 2011).

In addition to special education, efforts are being made to promote inclusion education initiatives in Zambia, where CWID are integrated into general education settings. Inclusive education became formally institutionalized in 1996 with the Ministry of Education's national policy, Educating Our Future. This policy established that "to the greatest extent possible, the Ministry will integrate pupils with special educational needs into mainstream institutions and will provide them with the necessary facilities" (Ministry of Education, 1996).

While this policy appears promising, educational scholar Morgan Chitoyo says Zambia needs special education laws, not policies. Laws are significantly more authoritative and would allow for much greater specificity when it comes to funding, accessibility, and accountability (Chitoyo & Muwana, 2018). The policy does not provide a mechanism for measuring successful educational outcomes, making it difficult to assess the effect of the policy (Serpell & Jere-Folotiya, 2011). According to disability studies professor Judith Anne McKenzie, inclusive education as it is typically implemented in African settings is not as inclusive as the concept implies since “it is largely unsupported and unresponsive the individual pupil’s need for learning support” (McKenzie, 2013). When kids with disabilities are placed in mainstream classrooms, they are also frequently ostracized by their peers (Nabuzoka & Rønning, 1997). All of these barriers to accessing education leave CWID isolated from the community and without the opportunity to learn like other children. This only increases the burden of care for their parents.

Lack of Parental Support

Families and communities play a crucial role in addressing the needs of CWID, as well as advocating for an inclusive society and the protection of their children's human rights (Emerson, McConkey, Noonan, & Felce, 2008). As the parent of a CWID, the essential responsibilities entailed require an extremely close-knit, intimate relationship between the parent and the child in order to successfully progress towards that child’s sustainable growth and maturity. However, parents experience high levels of stress due to several factors, such as time constraints, financial hardships, relationship strains, and lack of support in general.

Despite the unique stressors that parents of CWID face, there is no form of support to rely on to alleviate the heavy burdens they carry. Typically the mothers are the primary carers because they are considered to be responsible for their children’s behavior and there is a lack of involvement of other family members (Tsai & Wang, 2008; McNally & Mannan, 2013). These families are also shunned and isolated by the local community, and there are few accessible services. With the lack of familial support and the lack of support services single parents are forced to find personal ways of alleviating their stress.

With the lack of services that cater to the unique needs of CWID, parents must fill these roles in addition to their typical parenting responsibilities. Professionals at existing institutions are untrained, and parents experience a level of negligence from health care staff, according to a study done by Gona et al. (2010). Even when parents seek potential support and advice in caring for their children, the information they are given is “scanty or sometimes none at all” (Gona et al., 2010). Without sufficient information and formal support from services, parents adopt roles that are atypical for mothers, such as “developmental interventionist and liaison among multiple health care workers and family members” (Chiluba & Moyo, 2017). Consequently, it is very likely for parents to feel overwhelmed by the wide range of roles they might feel unqualified or unprepared for.

In addition to providing extra care for their children, "parental caregivers must also deal with feelings of guilt, separation from society, depression, marital problems, anxiety about their children's future and so on" (Tsai & Wang, 2008). Such emotion-focused problems not only hinder the child's progress but also disrupt the family dynamic. Furthermore, children are expected to provide for their families, care for their parents when they are of old age, and protect their own wellbeing. However, when parents realize their children have a disability, they feel that any expectation of a prosperous future is unachievable (Gona et al., 2010). Parents then question if caring for their children is worth it. Such internalized negative attitudes influence the children, the families, and the parents themselves. According to a study done in Kenya, 79% of caregivers of children with ID were at risk for clinical depression (as cited in Aldersey, A. Turnbull, & H. Turnbull III, 2016). With no support available, parents are left to face these emotional challenges alone.

A large component and source of parent stress roots from insufficient time for household chores, community junctions, and leisure (Chiluba & Moya, 2017; Gona et al., 2010). Most of the parents' time is spent on caring for their children, yet they struggle to meet their needs, which causes the parent to feel additional strain (Gona et al., 2010). Furthermore, they do not see the child as a problem or burden, but rather it is their own inability to meet the needs of the child that creates the most stress (McNally & Mannan, 2013). But because most of their time is spent on attending to the child at home, parents have insufficient time for other chores and are isolated from community obligations (Gona et al., 2010; Aldersey et al., 2016).

While caring for CWID with a lack of support leads to parent stress in itself, the cost of caring for a child with a disability is also very high, creating another challenge. The primary caretakers of CWID are primarily single mothers and experience "extreme economic pressure as they are not able to seek work given the demands of caring for their child." (McKenzie, 2013). This is described as double burden poverty in that these mothers experience double the burden of poverty due to the high cost, in terms of time and money, of caring for CWID (McKenzie et al., 2013). With insufficient funds to satisfy their children's needs, parents also experience difficulty acquiring basic needs, such as food, clothing, fees, and money for drug treatments, as well as services including healthcare, education, and transport (McNally & Mannan, 2013).

Options for Support

Given the important role that parents play as their child's primary caregiver, it is important that they are actively supported and included in interventions surrounding their child’s development.

Dr. Parminder Raina emphasizes the importance of family-centered interventions. Caregivers play a big role in the child's life, and thus should be a central part of any rehabilitation program (Raina et al., 2005). Community-based rehabilitation (CBR) is one intervention that follows this focus. CBR is delivered within the community using local resources, targeting rehabilitation in five areas: health, education, livelihood, social, and empowerment. (Iemmi et al., 2013).

An important aspect of CBR is "the transfer of skills to family members" (Mckenzie et al., 2013). CBR has frequently shown that when formal specialists are inaccessible, parents themselves can act as successful teachers of their own children, if given proper training and support (Helander, 1993 as cited in McConkey et al., 2000). Parent training can be an effective way to both improve child development and increase the parent's self-efficacy in caring for their child. After attending a training workshop in Lesotho for relatives of PWID, participants reported feeling more confident and empowered. They began running workshops in their communities, training parents and community workers in disability rights, how to work with professionals, and how to teach their children self-help skills (McConkey et al., 2000). Parent training can also help improve the parent-child relationship by reducing parental stress and increasing the child's self-sufficiency (Machalicek et al., 2015). However, most of the studies centered around training programs for parents of CWID are based in North America and Europe. Typically, participants in these studies are white, economically secure, and more likely to be formally educated. Beyond the McConkey study, there was limited information available on formal parent training programs in Africa.

PSGs are also another avenue through which parents can gain skills and receive support. As previously mentioned, the demands of caring for CWID can generate a lot of parental stress (Jackson et al., 2018). PSGs can help reduce this stress and provide a number of other benefits to parents, including the opportunity to share experiences and information with one another and express their feelings and concerns (Nichols & Jenkinson 2006 as cited in Jackson et al., 2018). Particularly in developing countries, where limited support is offered to parents of CWID, PSGs can become an important source of emotional support and solidarity, encouraging parents to work together to advocate for their children's rights (McConkey et al., 2000). According to the Jackson study, 64% of parents interviewed said that support groups "offered some level of value and were beneficial" (Jackson et al., 2018). A majority of the participants highlighted the importance of a PSG as "a place where you can go to gather information." (Jackson et al., 2018). It was also recommended that PSGs "offer concurrent child-care services" to ensure that parents are able to attend meetings (Jackson et al., 2018).

While studies like Jackson's provide a useful perspective on PSGs, they have limited application to the Zambian context. Similar to the literature on parent training, studies on

PSGs, or parent support in general, are often conducted with white, affluent parents in Western countries

(Aldersey et al., 2016). We were only able to find a few studies focusing on PSGs or parents' associations in Africa. One study conducted by Heather Aldersey and her colleagues looked at a self-help association based in Kinshasa, Democratic Republic of the Congo (DRC) called Association Nationale des Parents des Enfants vivant avec Handicap Mental en RDC [National Association of Parents of Children Living with Intellectual Disability in the Democratic Republic of the Congo] or ANAPEHMCO.

ANAPEHMCO provides emotional, informational, and material support to its members through home visits and assistance with healthcare expenses. The study highlights the advantages that locally-run support groups have in meeting the needs of parents in the community:

> This specific grounding in local cultural norms of interpersonal interaction and the shared experience of being a parent of a child with IDD gives ANAPEHMCO members a unique perspective in identifying problems and delivering solutions without being intrusive or inappropriate. Often, solutions to problems proposed by ANAPEHMCO members have undergone real-life testing by other families. (Aldersey et al., 2016)

However, a drawback to being highly local is that ANAPEHMCO struggles to find sustainable sources of funding (Aldersey et al., 2016). Local associations like ANAPEHMCO may struggle to gain members since the stigma against ID in countries like the DRC and Zambia can deter parents from affiliating with such organizations (Aldersey et al., 2016). For families who are severely resource-limited, an organization that requires time commitment and affordability may not be a realistic option (Aldersey et al., 2016).

Methods

The findings of this paper were drawn from both a comprehensive literature review and interviews with relevant stakeholders. The goal of this literature review was to gain a clearer understanding of ID in the Zambian context and current ways that parents of CWID are offered support. This review allowed for identification of gaps in existing research.

Stakeholder interviews were conducted to directly address the question of how to best support parents of CWID and to fill the knowledge gaps that were identified in the literature review. Fourteen interviews were conducted with stakeholders from non-governmental organizations (NGOs), government agencies, schools, and other expert groups. Interviews were conducted in-person or over the phone with guidance from the Southern African Institute for Policy Analysis and Research (SAIPAR) and the Special Hope Network (SHN).

Prior to the interview, stakeholders were asked to sign a consent form indicating their agreement to participate in this study. Responses were audio-recorded if the interviewee consented.

Interviews were designed to cover three main subject areas: the challenges parents of CWID face in their community, the stakeholder's unique programs and efforts, and the interviewee's opinion on specific parent support interventions, including parent training, assessment tools, and components of a successful PSG. The responses addressed diverse areas of parent support.

Overall, these findings facilitated a more comprehensive and detailed understanding of the barriers in accessing support and identified important components for future initiatives. The responses addressed diverse components of parent support.

Findings

Lack of Support: Root Causes

In order to understand the best ways to support parents of CWID, it is necessary to first identify the barriers that they face in caring for their children and the areas in which they currently lack support. In our interviews with stakeholders, we asked them to identify the challenges parents currently face. We have outlined some of the most significant ones below.

Cultural Stigma

When interviewees were asked what primary stressors parents of CWID experience, the most common response was cultural stigma, and a representative from the Zambia Association for Parents of Children with Disabilities (ZAPCD) identified stigma and discrimination as the primary challenges parents face[1]. ID is viewed as witchcraft, taboo, a curse, or a punishment from God[2] across several countries in Africa where a number of our interviewees work.

Consequently, CWID are called derogatory names[3], and the associated shame cascades into discrimination and social exclusion, according to a representative from UPPID.

Several interviewees emphasized that mothers are typically abandoned by their husbands and shunned by the community as a result of the cultural stigma surrounding ID. The child is seen as untouchable by other family members who hold these stigmatized views, and family members oftentimes feared that other pregnant mothers in the family would give birth to a CWID in their

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[1] Personal communication with a representative from ZAPCD on July 22, 2019

[2] Personal communication with Ric Law, Director of Disability Africa, on July 3, 2019, a representative from Zambia Association for Children and Adults with Learning Disabilities (ZACALD) on July 11, 2019, a representative from Ethiopian National Association on Intellectual Disabilities (ENAID) on July 15, 2019, & a representative from Zambia Federation of Disability Organizations (ZAFOD) on July 18, 2019

[3] Personal communication with Fabian Mambwe, Senior Rehabilitation Officer of ZAPD on July 16, 2019

presence[4]. Due to these superstitious beliefs, CWID are sometimes verbally and physically abused by their family members[5]. With a disrupted family dynamic and marital issues, mothers of CWID experience immense stress as a sole caretaker living with a lack of familial support.

Beyond the family, the mothers and their children are also largely discriminated against by their local community[6]. Such negative attitudes rooting from cultural stigma lead to complete isolation and exclusion from intimate guidance and support, as well as from essential services and resources[7]. The Church and neighboring families are the primary groups of social support in Zambia[8], but mothers of CWID are typically rejected and shunned from these communities, according to Ric Law. With a lack of a social support network, mothers feel hopeless and alone in managing their children at home and overcoming their personal challenges. Excluded from mainstream society in a variety of ways, mothers struggle to seek the support they need to change their own mindset and meet their children's needs.

The cultural stigma that is exerted by family members and local community members is also internalized, and mothers direct self-stigma towards themselves and their children.[9] According to a representative from PODCAM, they feel out of place, unable to fit in with other families and their surrounding community. Such dissonance causes mothers to feel low levels of self-esteem in terms of their own abilities to care for their children, which discourages them from making efforts to seek resources and support. In addition to doubting their own abilities, mothers tend to doubt their children's capabilities because they see the child as untrainable or incapable of becoming productive members of society, according to Mary Nkhoma.

Furthermore, many interviewees described how the impact of cultural stigma not only impairs relationships amongst the family and the community, but it also prevents the mother from feeling attached to her child. Due to the self-stigma and community shaming, mothers are unable to accept their child's condition and the stigma that comes with it.[10] As a result, mothers find themselves in the dilemma of deciding whether to abandon their children or to continue to care for them in isolation under extreme social pressure.[11] According to Ric Law, in extreme cases,

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[4] Personal communication with Theresa Makwara, coordinator of Zimbabwe Parents of Handicapped Children Association (ZPHCA) on July 8, 2019

[5] Personal communication with Theresa Makwara (ZPHCA)

[6] Personal communication with a representative from Parents of Disabled Children Association of Malawi (PODCAM) on July 10, 2019 & a representative from ZAFOD

[7] Personal communication with Mary Nkhoma, Programme Officer of Cheshire Homes Society of Zambia (CHSZ), July 9, 2019

[8] Personal communication with Ric Law (DA) & a representative from ZAPD on July 16, 2019

[9] Personal communication with Mary Nkhoma (CHSZ)

[10] Personal communication with Dr. Kenneth Kapalu Muzata, Doctor of Education at the University of Zambia

(UNZA) on July 12, 2019

[11] Personal communication with Ric Law (DA)

there have even been scheduled killings of CWID in certain communities When mothers choose to continue to care for their children, the CWID are often treated with neglect and abuse due to the emotional and financial burdens the mothers face. CWID are hidden away at home as mothers refuse to show the public that their child has the “cursed” disability. Unable to leave the home, CWID are completely obstructed from opportunities to interact with others.[12] Intentional isolation of the child and stigma-driven isolation of the family ultimately result in a hindrance in the child’s growth and learning process and potentially even a regression of the disability.[13]

Ultimately, many of the interviewees had identified the stigma surrounding ID as the primary barrier to support for parents of CWID. Originating from traditional witchcraft beliefs, the stigma and consequent social isolation are facilitated on a large scale, restricting access to the services needed for the protection of the mother and child’s basic well-being.

Double Poverty

An issue identified in our literature review that many of our interviewees reiterated is the high poverty rate amongst parents who have CWID. This is often the result of a phenomenon that Salome Francois identified as “double poverty.[14]” Since mothers are often abandoned by their husbands and shunned by their families, they are left to care for their children almost entirely on their own. CWID usually require constant care, so mothers have very little time to work outside of the home.[15] This severely limits their ability to earn an income and support their families. The cost of care for a CWID is also higher than for typically developing children due to the extra services that they require.[16] The combination of increased expenses with limited available working time places a high financial burden on many mothers, leaving them unable to sufficiently provide for their children and themselves.

Lack of Government Intervention

A number of our interviewees identified governmental support as an area that is lacking significantly in their country. Since our interviewees are based in over six different countries, it is difficult to make generalizations based on their responses and apply them to Zambia.

Stakeholders in Ghana and Zimbabwe both emphasized the need for greater awareness and

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[12] Personal communication with a representative from ZACALD, a representative from ZAFOD, & a representative from ZAPCD

[13] Personal communication with Fabian Mambwe (ZAPD) on July 16, 2019

[14] Personal communication with Salome Francois, Executive Director of New Horizon Special School in Ghana on June 28, 2019

[15] Personal communication with Mary Nkhoma (CHSZ), Barbra Phiri (ZACALD), and Fabian Mambwe (ZAPD)

[16] Personal communication with Theresa Makwara (ZPHCA)

education on disability within the government itself in order to facilitate better policies[17] Our interviewees based in Zambia also identified areas where government intervention is not implemented as effectively as it should. A representative from ZACALD highlighted the lack of subsidy support available specifically for parents of CWID.[18] The Zambian government does run a social cash transfer program that provides financial support to poor, vulnerable families, including households with disabled members, but this support is not provided to every family in need and it can be difficult to track how many parents of CWID are receiving those benefits.[19]

Another issue is the lack of implementation and enforcement of existing laws in Zambia. The Zambian government has passed a lot of legislation protecting the rights of PWID, but people's rights continue to be violated. An example of this is that CWID have the right to be educated in the most inclusive setting possible, but according to a representative from ZAFOD, CWID are often denied admission to school by teachers and administrators.[20] This lack of enforcement, coupled with a lack of awareness about their children's legal rights, makes it very difficult for parents to send their children to school.

These basic public services like education and healthcare remain largely inaccessible to CWID, which makes it very difficult for parents to adequately care for their children. Some CWID have motor function impairments that prevent mobility. Due to the unaccommodating nature of transportation services, parents are forced to either physically carry their child or keep them at home.[21] In terms of access to education, there is a lack of existing opportunities of education for CWID in the first place. Specifically, there is a lack of special education schools and teachers, which was reflected in our literature review and through several interviews with stakeholders in Zambia and in other countries.[22] When CWID are sent to school, they face a lot of challenges, including social ostracization.[23] Since children are not adequately included in school, educationally or socially, some parents believe their child's best option is to be removed from school altogether. However, if the child does not attend school, the child's development and sense of independence are hindered, only increasing the parent's burden of care in the long run.

Parents also struggle to access healthcare services for their children. CWID often require a range of health services depending on their unique needs, but before they can receive those services, their needs have to be identified through an assessment. One of the biggest barriers parents face

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[17] Personal communication with Salome Francois (New Horizon Special School in Ghana) & Theresa Makwara (ZPHCA)

[18] Personal communication with a representative from ZACALD

[19] Personal communication with Dr. Kenneth Kapalu Muzata (UNZA)

[20] Personal communication with a representative from ZAFOD

[21] Personal communication with Joyce Inambao (BSNP)

[22] Personal communication with Fabian Mambwe (ZAPD) & Theresa Makwara (ZPHCA)

[23] Personal communication with Manel Mhiri from Inclusion International on July 8, 2019

is a lack of access to these assessment services. Dr. Kenneth Kapalu Muzata explained that there is an assessment center at the University of Zambia, a public university, but many parents are unaware of its existence.[24] If a parent cannot identify their child's disability, they would be unaware of their needs or what services to look for in the first place. They are also likely to misunderstand the child, and this lack of knowledge can sometimes leads to abuse.[25] The underlying problem in these inadequate services, according to some of our interviewees, is the lack of inclusivity in existing laws in Zambia. Even government representatives acknowledged the need to integrate the perspectives of PWID into every area of government policy to ensure that when these services are designed and delivered, they are accessible to everyone.[26]

Current Interventions

After detailing the barriers to support that parents face, the next step is to identify current interventions that provide parents with support in the areas that they need it most. We spoke with stakeholders who are carrying out this work themselves, as well as experts with knowledge of current efforts. Some of these initiatives are provided by NGOs, while others are generated within the community through DPOs or parents' associations. They include projects such as the formation of PSGs, economic empowerment programs, parent training workshops, and capacity-building initiatives. While some of this work is being carried out in Zambia, we also analyzed interventions in other African countries with the aim of applying them to the Zambian context. We have reviewed these interventions below, while also acknowledging the challenges that organizations face in implementing them successfully.

Parent Support Groups

Purpose and Benefits

As disability studies professor Judith Anne Mckenzie and her colleagues have pointed out, "family and community care remain the commonly available option" in places like Zambia, where formal government services are insufficient in assisting parents (Mckenzie et al., 2013). PSGs act as a network through which this informal, community support can be provided. Eight of the stakeholders we spoke to either facilitate the formation of PSGs or run their own. Even the stakeholders who do not work directly on PSGs were able to provide their opinions on them based on their experience in the field of ID. The PSGs described by our interviewees often expand far beyond the typical Western idea of a support group. Since there is such a dearth of available services, PSGs in the African context appear to take on much broader scope than simply organizing regular meetings. The purpose of a PSG can vary widely depending on the

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[24] Personal communication with Dr. Kenneth Kapalu Muzata (UNZA)

[25] Personal communication with a representative from PODCAM

[26] Personal communication with a representative from ZAPD.

goals of the facilitating organization and the needs of the parents themselves. A PSG can be a place to share knowledge, resources, and personal experiences related to raising CWID.[27] However, it can also be a space where parents engage in income-generating activities, plan community education initiatives, or develop advocacy strategies. Our interviewees describe a wide range of benefits that PSGs can provide parents. One of the most important ones is a source of emotional relief and social support. By connecting with other parents in similar circumstances "they realize that they are not alone."[28] PSGs give parents the space explore and communicate their feelings about raising their children.[29] Parents can also learn from each other through PSGs by interacting with fellow parents facing similar challenges and learning from their unique coping solutions.[30]

PSGs can also encourage greater acceptance of CWID within the family. Multiple interviewees had observed parents whose acceptance and understanding of their own children increased through their participation in a PSG. Dr. Muzata called PSGs "crucial" in helping parents accept their child's disability.[31] Salome Francois described how through the Parent Association of Children with Intellectual Disability - Ghana (PACID - Ghana), "parents realize that these children are not animals… they're also human beings and deserve to be treated the same way as everyone else.[32]" Theresa Makwara explained that parents who joined ZPHCA began to see how valuable their children were through their participation in the group.[33] This shift in attitude often comes from the increased knowledge about their child's disability that a PSG can provide. Once a parent understands their child's abilities and limitations, they are better able to accept them for who they are.

Our interviewees also pointed out that the formation of a PSG can also be an avenue through which parents raise awareness on ID in the community and advocate for their children's rights. The PSGs run by PODCAM lobby to increase inclusive education services and facilitate greater inclusion of their children in local activities.[34] Multiple interviewees highlighted the potential strength and impact that a group of parents can have on their community. Parents can be powerful advocates for their children, working with local leaders to help educate the community and reduce the stigma their children face. Parents can also engage in peer-to-peer advocacy, sharing knowledge about the rights of CWID within the group and empowering all of the parents

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[27] Personal communication with a representative from PODCAM, a representative from UPPID, Mary Nkhoma (CHSZ), & Joyce Inambao (BSNP)

[28] Personal communication with a representative from UPPID

[29] Personal communication with Ric Law (Disability Africa)

[30] Personal communication with a representative from PODCAM

[31] Personal communication with Dr. Kenneth Kapalu Muzata (UNZA)

[32] Personal communication with Salome Francois (New Horizon Special School in Ghana)

[33] Personal communication with Theresa Makwara (ZPHCA)

[34] Personal communication with a representative from PODCAM

to defend their children's rights whenever they are violated.[35] Regardless of the purpose, all PSGs allow parents to come together and brainstorm solutions to the problems that they and their children face.[36] Parents have the best understanding of their own issues, and when they work together, they can generate solutions to benefit the whole group.

Components of a Successful PSG

Our interviewees identified a number of important elements to consider when forming a PSG in order to ensure that it is as valuable to its members as possible. A key issue raised by multiple interviewees was the need for a common purpose that unites all members.[37] The PSG needs to have a clear set of goals that all the parents have agreed upon. They need to understand what the group's goals are and how they can personally play a role in achieving them. It is important that PSGs are self-motivated and self-organized.[38] Parents will not actively participate in the group, or maintain it in the long-term, if they feel coerced into forming it. A successful PSG also needs a clear leader, or leadership team. Ideally, these leaders should be parents themselves with the necessary knowledge and skills to guide the group.[39] The group should have a structure to its meeting times, and ensure that members are able to attend meetings.

A successful PSG was also identified as one that does advocacy in the local community, fostering productive discussions among members and educating the wider community in order to combat some of the stigma associated with ID.[40] The more the local community accepts CWID, the more support they will provide to parents, which would ease some of their burden of care. As a representative of ENAID noted,"That's how you see a support group is strong -- solving each other's problems." If a PSG can reduce some of the stigma that their members struggle with, it is successfully supporting those parents.

A few interviewees also argued that a PSG needs an effective capacity to run. Not only does a support group need enough members to function effectively, but it should also be connected larger local and national support networks. These networks allow smaller PSGs to support and learn from each other.[41] Effective capacity also means that PSGs should be connected to other community institutions, like religious groups, schools, or government agencies. This is significantly important because parents often turn to these more established institutions first, so these groups would be able to refer new parents of CWID to the support group.[42] Resources are

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[35] Personal communication with a representative from ZAFOD

[36] Personal communication with Joyce Inambao (BSNP)

[37] Personal communication with Mary Nkhoma (CHSZ), a representative from PODCAM, Dr. Kenneth Kapalu Muzata (UNZA), & a representative from ZAPCD

[38] Personal communication with Manel Mhiri (Inclusion International) & a representative from ZAPCD

[39] Personal communication with a representative from ZAPCD & Dr. Kenneth Kapalu Muzata (UNZA)

[40] Personal communication with a representative from UPPID & Joyce Inambao (BSNP)

[41] Personal communication with Manel Mhiri (Inclusion International)

[42] Personal communication with Dr. Kenneth Muzata (UNZA)

also vital to the economic viability of a support group and its members, and some interviewees identified support groups as a place where parents can work on income-generating activities together to financially support the group and the parents themselves.

Strengthening Networks

A key component of PSGs is connecting parents with one another, with partner organizations, or with government agencies. Many interviewees found value in using collaborations as a tool to facilitate large-scale change. A representative from UPPID and a representative from ENAID described a strong network with partner organizations as an integral part of the programs they offer in their respective organizations, connecting parents with other DPOs and NGOs that provide the exact services they need for their child's specific disability.

Networking among parents themselves, either within the organization or through outreach efforts, promotes capacity-building of PSGs, which contributes to the formation of a powerful network of information exchange and enhanced peer support[43]. Strengthening the network also allows for organizations to reach parents in more rural or isolated areas of the country by extending through members' personal connections,[44] providing opportunities of support to those who typically receive very little.

Furthermore, as a federation of organizations, ZAFOD is primarily responsible for coordinating, monitoring, and providing platforms for idea exchange for their partner organizations.[45] When asked about the positive effects of successful coordination among organizations, a representative described how organizations working together towards one common goal allow them to share resources collectively, ensure success of implemented programs, and have their voices heard as a unified community. Overall, coordination and collaboration benefit the parents and the organizations themselves by strengthening efficiency and efficacy.

A strong network among parents and other organizations is a fundamental tool for DPOs and service providers to effectively fulfill the needs of parents and CWID in terms of expanding available opportunities, providing a community of fellow parents with CWID, and inspiring parents to advocate for their children's rights to push against the oppression that cultural stigma causes.

Facilitating Inclusion

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[43] Personal communication with Manel Mhiri (Inclusion International)

[44] Personal communication with a representative from UPPID

[45] Personal communication with a representative from ZAFOD

According to Ric Law, “in order for inclusion to happen, we need equity, which means doing things with regard to individual differences, not regardless of.” Inclusion of CWID is critical to increasing their access to support and protecting their human rights. As described previously, CWID and their families are excluded from a variety of community activities and are limited in exercising their rights. Efforts to make such opportunities more accessible have been made through the establishment of specialized services. However, Law argues that characterizing CWID as “special” only reinstill their segregation from the rest of society. Furthermore, inclusion and cultural context were emphasized by Law as critical aspects to consider for program efficacy. Without the genuine inclusion of CWID and careful consideration for unique context, any intervention would be relatively ineffective and irrelevant.

The local communities the CWID are raised in are considered to be the “number one ambassadors” for these children, according to a representative from UPPID. The first step to catalyzing efforts to create an inclusive environment is by educating and encouraging the community to understand and accept the CWID. Salome Francois recommended educating community members such as clinicians, teachers, policemen, and the media in order to increase access to the services those community members provide. Additionally, UPPID incorporates interactions with the local community in the skills training programs the organization offers.[46] Self-advocacy is a fundamental tool for initiating inclusion efforts in the community by raising awareness to the impact of stigma and shame, which is normally hidden[47].

In addition to efforts facilitating inclusion in the local community,ten of the stakeholders interviewed advocated for inclusive education. Despite the prominent advocacy efforts, the importance of inclusive education and its benefits are unknown to a large number of parents of CWID, according to Dr. Kenneth Kapalu Muzata. This is partly due to the fact that parents are not provided with adequate information about inclusive education, as well as poor implementation of the proposal itself.[48] Furthermore, a “smaller learning environment with individualized educational focus” was suggested by Dr. Muzata to strengthen the inclusion aspect of inclusive education. Inclusive education is a significant potential intervention that could make education more accessible to CWID, as long as it is successfully implemented and monitored.

Beyond changing the formal education curriculum, some interviewees acknowledged playschemes as an effective inclusive intervention. Playschemes represent a safe space for CWID to learn and grow through a natural and gradual process. In these spaces, CWID are able to interact with other children, with or without disabilities, building the essential socialization

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[46] Personal communication with a representative from UPPID

[47] Personal communication with a representative from UPPID

[48] Personal communication with Dr. Kenneth Kapula Muzata (UNZA)

skills they need for inclusion.[49] Disability Africa focuses primarily on implementing playschemes, and one of the main challenges is convincing parents of the high value and efficacy of playschemes. Law states that "play is under-valued, as well as inclusion, because culture screams the opposite." One of the key benefits of playschemes is its ability to contradict the stigmatized beliefs communities have towards ID and to show the community that CWID are able to adopt useful, utilitarian skills, even in a low-income environment.[50]Additionally, Mary Nkhoma from CHSZ suggested playschemes as a necessary tool parents need to be supported.

From inclusive language to playschemes, the diverse array of interventions that specifically aim for inclusion seem to have positive results from our interviewees' responses. A common theme underlying these efforts is the emphasis on education and awareness. Without a common understanding of ID and the CWID themselves, the discrimination they face cannot be effectively addressed.

Parent Education

Parent education is an effective intervention utilized by several of our stakeholder organizations. In a typical parent training model, parents are taught the basic skills they need to care for their children independently at home. Most of these skills are used to teach children self-help activities like cooking, hand washing, and several other daily tasks. One of the main benefits of parent training is its ability to bridge the knowledge gap. Part of teaching parents caregiving skills also involves educating them on ID more generally, allowing them to spread that information to their families and communities. Through parent training, parents are also able to closely interact with their children in a positive way. They are able to see firsthand that their children are capable of growth and development just like any other.[51] Some of our stakeholders also utilize different forms of parent education centered on capacity-building and intellectual disability awareness.

PODCAM has implemented a form of parent to parent training, where parents are selected to become trainers of other parents. These selected parents receive instruction on the national level in order to become trainers themselves to local PSGs in their communities. This kind of
peer-training model allows for parents to not only master their skills by teaching others, but it also creates a stronger peer support network by having parents help each other directly. ZPHCA facilitates similar support networks through parent training by teaching parents to become skilled caretakers for different CWID, not just their own child. This allows parents within the group to leave their children with each other, giving them the time to make an income or complete other

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[49] Personal communication with Ric Law (DA)

[50] Personal communication with Ric Law (DA)

[51] Personal communication with Theresa Makwara (ZPHCA)

necessary household tasks. ZACALD runs a form of parent training centered around capacity-building and advocacy; in their program, they teach parents strategies to lobby for the basic rights of PWID as a way to empower parents to speak up for their children and themselves. A few organizations, like the Bauleni Special Needs Project (BSNP), use a form of home-based education, training parents to assist their children with skill development within the home environment. These forms of parent training all revolve around the main objective of equipping parents with a strong sense of confidence and readiness when supporting and caring for children with intellectual disabilities.

Economic Empowerment

In addition to teaching parents how to care for their children independently, parents are also taught how to provide financial stability for the family. Since a majority of the primary caretakers of CWID are single parents, a significant portion of their stress derives from the heavy financial burden. This burden directly influences the care parents are able to give to their children. The high cost of services and materials needed to care for CWID and the struggle of finding a job that pays enough to cover childcare expenses makes providing sufficient care very difficult. To alleviate such financial constraints, some stakeholders provide an economic empowerment program to their members. PODCAM and CHSZ highlight the need to provide income-generating opportunities for their parents so that they can better support their children in a sustainable manner.

There are diverse interventions that organizations have implemented for the purpose of empowering single parents with indirect financial support. ENAID specifically offers an Economic Empowerment Program that equips parents with the basic skills they need to join the workforce and connects them to other organizations that can provide employment. The parents are also counseled on ways to start their own businesses.[52] ZAPCD provides an entrepreneurship program to allow parents to launch their businesses directly from home,[53] allowing for parents to look after their children while simultaneously earn income. Furthermore, a representative from ZAPCD also introduced village banking as a way for parents to save money collectively as a unified PSG,[54] incentivizing parents to be involved in the PSG.

From the responses our interviewees gave, we found that financial support and empowerment directly correspond with one another. Once parents are financially stable, they are able to fulfill the needs of CWID and advocate for the protection of their rights.

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[52] Personal communication with a representative from ENAID

[53] Personal communication with a representative from ZAPCD

[54] Personal communication with a representative from ZAPCD

Challenges in Implementation

While reviewing the various interventions currently implemented across Zambia and other African nations, our stakeholders acknowledged that there are a number of challenges they face when executing their programs. One of the biggest obstacles by far remains the negative cultural attitudes towards disability. Although the stakeholders we spoke with are doing admirable work to combat this stigma, it is impossible to undo years of negative cultural beliefs in a single project, or even in a single generation. It will take a lot of time to change the collective understanding of ID and reduce the stigma and discrimination that PWID face.[55]

Another issue identified by nearly every interviewee was the lack of available funding. There is very little donor or grant funding available to the organizations that work directly with parents and CWID, making it difficult for them to sustain their projects in the long-term.[56] Many of the organizations we spoke with identified projects that they would like to implement, but are unable to due to funding limitations. Another challenge is managing the expectations of the parents they serve, which is something that a representative from UPPID spoke about. Since parents deal with so many difficulties on a daily basis, they often expect organizations, schools, and government agencies to solve all of their problems, especially financial ones. As much as these organizations strive to support parents as much as possible, they simply do not have the capacity to resolve every issue that arises, and often struggle to help parents understand the ways in which they can be helpful to them. When it comes to parent training and PSGs, stakeholders have identified that finding the right parents to lead a support group, or teach other parents, can be a challenge. The lack of education and higher illiteracy levels in the rural areas of some countries has been identified as a particularly difficult barrier to overcome when asking parents to train or lead other parents.[57]

Recommendations

While there are many interventions in place, there are challenges and areas of improvement that need to be addressed in order for these interventions to be successfully and effectively implemented. To fully address the needs of parents of CWID, we must consider potential solutions or alternatives to the challenges and gaps that currently exist in parent support efforts. There are a wide variety of ways parents can be better supported, whether it be through new intervention ideas or strengthening existing ones such as parent support groups. Below we have outlined the specific ways in which we recommend that these interventions be implemented in order to ensure their efficacy.

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[55] Personal communication with a representative from UPPID

[56] Personal communication with Salome Francois (New Horizon Special School in Ghana), a representative from ZACALD, and a representative from ZAFOD

[57] Personal communication with a representative from PODCAM

Expanding Parent Education

Stigma has been identified as the root cause for the lack of parent support, but this root cause ultimately stems from the lack of knowledge about ID.[58] Due to the lack of knowledge, there is a lack of understanding and empathy, which escalates into abusive stigma and unequal treatment of CWID. When parents first discover their child has a disability, they "don't know where to go, where to get an answer, how to face everything," according to Manel Mhiri. Parent education provides guidance, networking, and emotional support to parents on an individual level, but it also plays a key role in inclusion and fostering a stronger sense of acceptance within the community and the family.

In addition to increasing opportunities of parent education, modifying the curriculum to encompass diverse subject areas would help solidify the education the parents receive. Ideally, parent education should train parents how to teach their children self-help skills,[59] provide connections to resources,[60] build an understanding of the legal rights of PWID,[61] increase knowledge about the disability itself, and teach parents to provide life-long support for their children.[62] From a comprehensive education curriculum, parents would not only feel confident in their ability to care for their children, but they would also be more accepting of them. According to a representative from ZAPCD, "once you accept that you have a child with a disability, that is the greatest tool that allows parents to move on." By providing opportunities for parents to adopt these diverse skill sets, parent education would thoroughly prepare parents as motivated carers and advocates for CWID.

Improving Parent Support Groups

While there is a lack of parent education, there is also a lack of PSGs in Zambia and other countries in Africa. Of the existing PSGs, many are also inaccessible to some families, whether it be due to geography or transportation costs. PSGs are crucial to directly supporting parents by creating a space for sharing experiences and concerns and providing solutions to their personal challenges.[63] While parent education is essential to parent empowerment, PSGs are necessary for immediate emotional relief and encouragement to take further action in meeting their children's needs.

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[58] Personal communication with Joyce Inambao (Bauleni Special Needs School)

[59] Personal communication with Dr. Kenneth Kapula Muzata (UNZA)

[60] Personal communication with Dr. Kenneth Kapula Muzata (UNZA)

[61] Personal communication with a representative from ZAFOD

[62] Personal communication with a representative from ZAPCD

[63] Personal communication with Manel Mhiri (Inclusion International) & a representative from ZACALD

PSGs provide immediate guidance, but they are also needed as a continuous source of support throughout parents' lives. Assessing whether a parent is ready to care for their child independently is a complex and unclear process due to the difficulty in defining parent readiness as a measurement. After speaking to our interviewees, we found parent readiness to be assessed a variety of ways: through children's progress and improvement, parents' confidence, parents' attitudes towards their children, and occasional follow-ups. Indirect assessment of parent readiness can be done through the child's progress in successfully performing certain activities.[64] If the child was progressing rapidly, it would mean that the parent was diligent and proficient in teaching the child the skills they need to improve.

On the other hand, parent readiness is also assessed directly through the parents' thoughts and feelings. Parents who are more open and confident about their child's disability or exhibit willingness and interest in supporting their children are considered to be knowledgeable about their child's disability and their needs.[65] Furthermore, parent readiness is assessed through a careful monitoring process, where feedback is received through either one-on-one conversations or group discussions in self-help or focus support groups that meet regularly.[66] However, while there are a variety of ways to assess parent readiness, a representative from ZAPD states that, "all parents are ready, but it's the environment that makes it difficult to provide optimal care."

After compiling the different ways of assessing parent readiness, we then considered how long parents would need to remain in a PSG or parent training program. However, assessing the length of parent participation is dependent on an extremely wide range of factors, including family background, cultural context, literacy of parents, poverty, the severity of the child's disability, and the parents' acceptance of the CWID.[67] Some interviewees provided estimates based off of their own experiences with their programs, which ranged from eight months to two years.[68] On the contrary, some interviewees viewed parent readiness and training as a continuous and ongoing process[69] -- there is no specific time that can be set for all parents to feel ready.
According to Manel Mhiri, "depending on the age of their children, [parents] face different challenges." Due to the diverse circumstances and unique backgrounds, PSGs are viewed by parents of CWID as an adaptable and stable support system that is always available for them when needed. To maintain PSGs as a continuous opportunity, PODCAM encourages parents

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[64] Personal communication with Salome Francois (New Horizon Special School in Ghana) & Joyce Inambao (BSNP)

[65] Personal communication with Mary Nkhoma (CHSZ), a representative from UPPID, & a representative from PODCAM

[66] Personal communication with a representative from PODCAM & a representative from UPPID

[67] Personal communication with a representative from PODCAM, Mary Nkhoma (CHSZ), and Joyce Inambao (BSNP)

[68] Personal communication with Theresa Makwara (ZPHCA), a representative from PODCAM, & a

representative from ZACALD

[69] Personal communication with Manel Mhiri (Inclusion International) & a representative from ZAPCD

who have been involved in the PSG for a long period of time to lead the PSGs and provide guidance and support for new parents.[70]

Peer-led PSGs, similar to the PSGs run by PODCAM, have been found to be most beneficial to parents, according to several interviewees.[71] Having support groups led by parents who experience similar challenges, PSG members are able to collaborate and create solutions that are catered to specific needs of parents and the appropriate cultural context.[72] With an underlying common purpose and unifying empathy, peer-led PSGs effectively achieve their goals in providing optimal support for parents of CWID, in addition to building a strong and expansive social support network that provides a wide range of unique benefits.

Furthermore, ZPHCA's caretaker training program highlights the need for established daycare centers for parents of CWID. There are several alternatives, such as the economic empowerment or vocational training programs, to address the problem of parents' inability to balance their limited time between childcare and work. However, training parents to be caretakers increases the versatility and flexibility of their skills of caring for CWID, while also providing assistance to other parents of CWID.[73]

In addition to improving the structure and organization of PSGs to better support parents and address their needs, there are a variety of ways outreach and monitoring efforts can be strengthened to improve the efficacy of the PSGs themselves. In terms of outreach, Dr. Kenneth Kapula Muzata suggested a creative approach in utilizing social media to share knowledge and interact with parents without any physical barriers. However, this also prompts the question of whether or not families would be able to access technology. Considering potential barriers, facilitating information exchange among the community and emphasizing the community's duty to accommodate PWID were identified as the most effective interventions to reaching out to community members and fellow parents.

Monitoring is an essential process that helps determine the trajectory for the next steps in addressing the encompassing issue of a lack of parent support, and efforts to monitor current programs' progress is currently lacking. With proper monitoring, effective interventions can be maintained and specific areas can be strengthened to improve efficacy,[74] while ineffective interventions can be discontinued and resources can be allocated to where they are needed most. Furthermore, government agencies and funding sources are unable to efficiently plan or

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[70] Personal communication with a representative from PODCAM
[71] Personal communication with Ric Law (DA), Theresa Makwara (ZPHCA), & a representative from ZACALD
[72] Personal communication with a representative from ZACALD
[73] Personal communication with Theresa Makwara (ZPHCA) & Manel Mhiri (Inclusion International)
[74] Personal communication with a representative from ENAID

distribute resources to partner organizations due to the lack of proper monitoring.[75] A simple method of baseline monitoring is implemented by UPPID, where follow-ups are conducted regularly at specific times, providing continuous care and attention to parents' and their children's progress.

Strengthening Economic Empowerment

Economic empowerment programs centered on parents exist as a developing intervention, but several stakeholders are hoping to implement income-generating activities for the CWID themselves. Alleviating the financial burden off of the parent, CWID are able to acquire valuable life skills while also contribute to earning money as financial support for their families, according to Salome Francois. A representative from UPPID compared skills training and cash incentives, both of which are means to address the financial concerns. Ultimately, skills training was valued over cash incentives because the skills would directly contribute most to the child's development and progression in the long run.[76]

In addition to supplementing CWID with utilitarian skills, vocational training also prepares CWID for employment, which increases self-sufficiency, empowerment, and inclusion. By adopting entrepreneurship skills, CWID are also able to strengthen their relationships with their primary caretakers. In the Bauleni Special Needs Project, students receive certification after completing their academic career and are able to seek formal employment related to their studies. Joyce Inambao of Bauleni Special Needs Project described the example of how students who study food and nutrition are able to work at Shoprite or Pick N Pay, the local grocery stores in Zambia. Vocational training not only provides direct benefits to the CWID themselves and their families, but it also plays a role in raising awareness to the equal capabilities of CWID. Therefore, there is an increasing need for employers to be educated and aware of the capabilities of CWID and for increased advocacy efforts focused on an inclusive workplace environment.

Building Community Support

Advocacy efforts begin with a strong community voice, but first and foremost, inclusion begins with the family. Several interviewees highlighted the importance of involving other family members in supporting the primary caretaker, as well as participating in caring for the child and advocating for their human rights.[77] Parents already lack external support, and stigma coupled with the lack of knowledge creates a disruptive family dynamic that causes tremendous amounts

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[75] Personal communication with Theresa Makwara (ZPHCA) & a representative from ZAPD

[76] Personal communication with a representative from UPPID

[77] Personal communication with Salome Francois (New Horizon Special School in Ghana), Theresa Makwara (ZPHCA), a representative from UPPID, & a representative from ZAPCD

of stress within the household itself. If siblings are educated on ID and the rights of CWID, they would be able to build close-knit, meaningful relationships between family members, as well as share efforts with the primary caretaker to advocate for equity and inclusion.[78] ZAPCD offers family-strengthening projects, which involve family planning, marriage counseling, and encouragement of male partner involvement. Such efforts are essential to addressing parent stress and creating an accepting environment in the home.

As CWID are more accepted into the family, the CWID and their rights are no longer hidden away from shame and embarrassment. Instead, the community is more aware of what the true cause of ID is and the potential CWID hold, contrary to the traditional taboo beliefs. This encourages community members and support groups, such as DPOs and PSGs, to not only understand but advocate for the rights of CWID using their own rights to voice their beliefs. Additionally, a representative from ZAPD emphasized the need for increased efforts to mainstream disabilities into diverse areas of society in order to build a cohesive community network for parents of CWID.

Increasing Government Support

Community engagement is a powerful mechanism for facilitating change through active cooperation by diverse community members and widespread information exchange. However, according to Mary Nkhoma, "there's only so much the community can do." As Nkhoma suggests, there is a need for equitable and inclusive policy and infrastructure in order for sustainable change to occur. With inclusive policies, CWID and their families would be supplemented with the necessary legislation needed to thoroughly convey the reality of ID on a national level through active awareness-raising and education. Such steady progress would allow for the oppressed and abused community to be treated as equals, no longer as demons or cursed beings.

In addition to inclusive policies, many interviewees expressed the need for funding, and it was suggested that financial support be provided by the government[79]. There is a lack of a budget allocated specifically for supporting PWID, and there is an especially high need for this equitable funding to alleviate the double burden poverty of families of CWID. With appropriate funding, new programs can be implemented, individualized support can be strengthened, and organizations would be able to better fulfill their missions. Furthermore, there is an emphasis on policy implementation. Many of the interviewees based in Zambia acknowledged the existence of legislation supporting the rights of PWID, but there is a lack of monitoring and effective

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[78] Personal communication with Theresa Makwara (ZPHCA)

[79] Personal communication with Manel Mhiri (Inclusion International) & Dr. Kenneth Kapula Muzata (UNZA)

implementation.[80] According to a representative from ZAPD, there is a need for available resources to be well-implemented and "accessible across all sectors."

As described in the literature review, there is a lack of government involvement in protecting the rights of PWD. While policies are in place and changes are gradually being made, there is a confusion on the duties that are expected of the government and the community. The Zambian Government is expected to provide social security to parents through policy implementation and subsidy support, according to a representative from ZACALD, in addition to actively ensuring that the rights of PWID are exercised and protected. Salome Francois states that the policies in place do not effectively promote inclusion, emphasizing the lack of equitable and financial support provided by the government. However, government agencies view the current situation from a different angle. According to Fabian Mambwe from ZAPD, a quasi-Government institution, strong advocacy efforts have been made and policies are in place -- "it's just a matter of how well the people are understanding and acting on their duties and rights." These contradicting expectations obstruct progress by relying on external support for large-scale change. Therefore, enacting positive change for the protection of the basic human rights of CWID is a duty that must be shared by both the powers of government at the national level and the influential community at the local level.

Limitations

It is important that we acknowledge the limitations that we faced when conducting our research, and how that impacts the utility of our findings. As American undergraduate students majoring in non-disability related subjects, we had limited prior knowledge on ID or on the Zambian political and cultural context surrounding it. Although we devoted significant time to learning about the issues touched on in the paper, someone with greater background in the subject or more field research experience may have been able to draw more useful answers from the interviews, or provide a more comprehensive analysis of the answers given.

The most tangible constraint we faced was the limited amount of time we had to complete the research. Although we were able to conduct fifteen interviews with stakeholder organizations in the two months we had, we would have been able to reach out to more stakeholders and likely gain greater insight on current and potential sources of parental support with more time. We also had to rely on stakeholder's descriptions of the parent support in rural areas of Zambia, but given more time and resources, we would have been able to conduct interviews with stakeholders working directly in those regions.

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[80] Personal communication with a representative from ZAPD and a representative from ZAFOD

Since our study also expanded to organizations in multiple countries across the African continent, the applicability of our results to Zambia specifically may be more limited. Although our interviewees described similar challenges faced by parents of CWID across different countries, there are still cultural, economic, and political differences between them that may allow some parent support interventions to be successful in one environment, but less so in another. Due to our lack of ethical and Institutional Review Board (IRB) clearance, we could not interview any parents of children with ID themselves. Some of our stakeholders were parents themselves, but we were only able to interview them about their professional experiences. As the primary stakeholder in this issue, it would have been valuable to include parent input in this paper, particularly when discussing the challenges they face and the solutions they would find most helpful.

Conclusion

Throughout this paper, we have established that parents of CWID in Zambia face a variety of financial, social, and personal barriers that prevent them from effectively caring for their children. We have identified a number of programs being implemented across multiple African countries that are attempting to dismantle these barriers and provide greater support to parents. Ultimately, we have used the input from our interviewees to generate a list of recommendations for strengthening, improving, and expanding current parent support efforts in Zambia. However, it is difficult for us to provide guidance on the specific implementation of these efforts since there are no available statistics detailing the number of DPOs or service providers that work with parents of CWID in Zambia. Without a set list of all organizations, we cannot know exactly what services are being provided or how many people they serve. There are also no updated statistics on the number of CWID in Zambia, or any reports detailing their financial and familial situations. Thus, we are unable to accurately assess all gaps in service provision. Future research formally identifying and surveying the existing organizations in Zambia and the population of CWID would allow us to better understand where the specific interventions we recommended are most needed.

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