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DECONSTRUCTING DISABILITY IN MALAWI: A MULTI-PERSPECTIVE QUALITATIVE STUDY ON UNDERSTANDINGS, POLICY DEVELOPMENT, AND POLICY IMPLEMENTATION

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ABSTRACT

Disability models serve as frameworks to conceptualize understandings of disabilities, influencing the creation of policies and programs. The United Nations, through the Convention on the Rights of Persons with Disabilities (CRPD), has established international standards influenced by disability models from the Global North. Despite Malawi's efforts to adopt the CRPD through numerous measures, people with disabilities still face challenges in accessing healthcare. The effectiveness of current policies in the health sector remains unclear. Therefore, it is crucial to consider local perspectives on disabilities, as well as differences in culture and livelihoods. This research employs thematic analysis to assess the perceptions of disability among policy makers and implementers—government officials, representatives from disability-related organizations, and health workers—in Malawi. It explores their perspectives on how disability policies have integrated international standards and been implemented to meet the needs of Malawians with disabilities. This multi-perspective approach reveals how understandings and perceptions of disability in Malawi are shaped by models from the Global North and various local factors such as type of disability, livelihood, and geographical region. The domestication of the CRPD and implementation interact with several factors, including financial and cultural contexts, knowledge of policies, and attitude differences among implementers, particularly health workers. This research contributes to the global knowledge base on disability perceptions, highlighting approaches to address disability issues and providing insights to inform policy makers in Malawi and other countries facing similar challenges. These insights may guide efforts to address implementation challenges and develop targeted trainings and awareness campaigns for implementers.

Introduction

This research explores how Malawian policy makers and policy implementers understand disability in the country. Specifically, I examine how perceptions and influences from the Global North affect disability policy domestication and implementation to improve health access and livelihood opportunities for people with disabilities in urban and rural settings. In this research, disability policy will refer to laws, policies, strategies, plans, and any other disability-related documents. In Lilongwe and Ntcheu District, I consulted a diverse range of individuals—government officials, disability-related organizations, and health workers—to assess their definition of disability, perceptions of disability in Malawi, and perspectives on how disability policies have been developed from international standards and implemented to meet the needs of Malawians. This work frames various disability models commonly conceptualized by the Global North to see if and how they exist within Malawi and address varied cultural contexts. The broader impacts of this research include contributing to the global knowledge base in disability studies, highlighting approaches to address disability issues and policies, and providing insights to inform policymakers in Malawi and potentially in other countries with similar cultural and economic contexts.

Disability models are crucial in helping people define disability in various circumstances. These definitions influence the application of this understanding in policy and program creation (Mitra, 2018) and shape how health workers treat patients with disabilities (Braathen et al., 2015). One significant instrument is the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), adopted in 2006 to center human rights and freedoms for people with disabilities (United Nations, 2006). The CRPD views disability as an "evolving concept" and defines it as "a long-term physical, mental, intellectual or sensory impairment, which, in interaction with various barriers, may hinder the full and effective participation in society of a person on an equal basis with other persons” (United Nations, 2006). The CRPD has influenced many African governments and activists to model domestic disability policies and legislation after it (Haang'andu, 2019). In 2007, Malawi signed the CRPD and ratified it in 2009 (UNTC, 2024). Before the adoption of CRPD, Malawi enacted the Handicapped Persons Act of 1971 to establish the Malawi Council for the Handicapped (MACOHA) to advise the government on disability affairs and promote rehabilitation services. As a signatory to the CRPD, Malawi has committed to aligning disability policies and laws with international standards and reporting to the UN about the status of people with disabilities in the country (Eide & Munthali, 2018). Following this commitment, Malawi has worked to acknowledge people with disabilities, who comprise 11.6% of the population above the age of five (“Convention,” 2023).

Malawi has several policies that domesticate the CRPD to protect the rights of people with disabilities. Domestication or localization refers to translating international standards into national policies and plans that can be implemented on the ground in communities (Grech et al., 2023). The most recent domestic measure is the Persons with Disabilities Act of 2024. This Act repeals the Disability Act of 2012 and the Handicapped Persons Act of 1971 (GoM, 2024), which saw disability only as a medical condition (GoM, 2018). The previous and the new Disability Act use the exact definition of disability as the CRPD. The Act states that people with disabilities have the right to health, employment, education, and more. In addition, it prohibits discrimination in these areas (GoM, 2024). While this legislation is a step forward, there is evidence that framings of disability from the Global North may not be suitable for the Malawian workforce and employment-related policies because of the different local contexts of the economy, culture, and politics (Wånggren et al., 2022).

In the health sector, despite having specific policies to protect the rights of people with disabilities, health access remains a challenge for them, especially in rural areas (Eide & Munthali, 2018). In addition to structural barriers such as cost and transport, negative attitudes from health workers are present towards people with disabilities (Harrison et al., 2020). Some healthcare providers have discriminated against patients with disabilities by refusing to treat them (Munthali et al., 2017). Due to the unclear effectiveness of current disability policies in the health sector, which Global North disability models have shaped, there is a need to consider local perspectives on disabilities and differences in culture and livelihoods. Therefore, this research focuses on perceptions of disability, how disability policies in Malawi have domesticated the international standards from the Global North, and how they are implemented to meet the needs of Malawians with disabilities. Understanding perceptions of disability may uncover any discrepancies between policy makers and implementers, which consequently contribute to shortcomings in policy implementation. For health workers who are directly interacting with patients with disabilities, knowing how they view disability may provide insight into the quality of care they give and potentially lead to targeted training and awareness programs to reduce discrimination towards patients.

Literature Review

This review addresses mainstream disability models from the Global North and their limitations. Next, it provides alternative models and factors that may better represent disabilities in an African context. Then, it explores access to livelihoods, education, and healthcare in Malawi, highlighting people with disabilities and rural areas. Lastly, it discusses current disability policies in Malawi and other African countries.

Disability Models

The medical model is a framework that sees disability as an illness, disease, or medical condition and emphasizes impairment stemming from the individual (Mitra, 2018). In healthcare settings, the medical model pushes providers to focus on the cause and consequences of disability to ‘fix it’ (Shakespeare et al., 2009). Braathen et al. (2015) found that rural healthcare workers, including traditional healers in the folk sector, doctors, and nurses, held a strong biomedical perspective in Malawi. They viewed the cause of disability as illness, accident, or congenital. To further explain the reason, traditional healers attributed disabilities to witchcraft or God’s will, whereas health workers in the professional sector did not. Nevertheless, these medical model views can prevent these patients from receiving the proper support they need to navigate society (Braathen et al., 2015).

Additionally, medical providers using this model may create categories based on their patients’ disabilities, which can reduce patient autonomy in treatment options (Barton, 2009). The relationship between providers and patients with disabilities significantly shapes the latter's perception of health access, which can affect if and how they use health services (Halvorsen et al., 2021). Ultimately, health workers using the medical model may overlook the broader context of disability, including factors such as stigma, structural barriers, and poverty—the major critique of this model (Shakespeare, 2014). Therefore, there is a need to transition towards other models to represent disability better to meet people’s needs.

The charity model sees a person as someone who needs to be pitied and is a victim of their disability (Amponsah-Bediako, 2013). People without disabilities should feel inclined to assist them and care for them out of their goodwill. Charity organizations often operate on this philosophy and focus on certain types of disabilities, which can be more harmful than helpful (Amponsah-Bediako, 2013). For donors, it can create an expectation of gratitude and cause them to limit options for their beneficiaries (Amponsah-Bediako, 2013). This mindset can be very detrimental to the self-esteem of people with disabilities because people may view them as helpless and reliant on others (Retief & Letsosa, 2018). With the charity model emphasizing care and concern, it can contribute to and reinforce discrimination and stereotypes. In the employment sector, the charity model may lead employers to focus on donations rather than an inclusive environment that allows people with disabilities to work and be empowered (Amponsah-Bediako, 2013). In Malawi, Remnant et al. (2022) saw that disability and education issues have been approached from a charity perspective due to the influence of missionaries. As a result, it has caused the government to invest less in disability inclusion activities (Remnant et al., 2022). Some NGOs have also operated under this model, leading to outdated employment training workshops for people with disabilities and preventing them from being competitive job candidates (Remnant et al., 2022). Although the charity model does create impacts on the ground, there is a need for more inclusive and empowering models.

The social model focuses on disability as a loss of opportunity due to societal and environmental barriers rather than individual impairment (Harpur, 2012). It separates impairment and disability; impairment is an abnormality in the body, and disability is the restriction that arises from social structures that lack and prevent the accommodation and inclusion of people with impairments in the community (Goodley, 2001). It emphasizes the societally produced exclusion and discrimination associated with disability, which can be remedied by social change (Lawson & Beckett, 2021). Although this model has pushed for increased societal inclusion, it has limitations. It creates a homogenous view of people with disabilities by disregarding the intersectionality of other marginalized identities, such as gender and race (Fitzgerald, 2006; Lawson & Beckett, 2021), and it can exclude cultural influences (Shakespeare, 1994).

Nevertheless, the use of the social model has paved the way for a better representation of disability and pushed society to be more inclusive.

The human rights model sees disability as stemming from society and centers on a person’s human dignity, addressing medical characteristics only as needed (Quinn & Degener, 2002). Some scholars believe that the human rights model of disability can improve the social model’s shortcomings (Degener, 2014) or complement it (Lawson & Beckett, 2021). Unlike the social model, Degener (2014) discusses how the human rights model can address different identities a person with a disability may have, such as gender, sexuality, race, acquired or congenital disability, and more. Most importantly, it provides a foundation for disability policies that protect human rights regardless of impairment or functioning capacity (Degener, 2014). Lawson and Beckett (2021) argue that the human rights model and social model are both needed to advance the disability movement and disability policy development. The social model effectively encourages people with disabilities to mobilize and increase representation. In contrast, the human rights model creates solidarity between people with and without disabilities. Lawson and Beckett (2021) conclude that the success of the human rights model depends on the social model, as they have two different focuses: the social model focuses on disability, and the human rights model focuses on disability policy.

Created by the World Health Organization (2001), the biopsychosocial model or the International Classification of Functioning, Disability and Health (ICF) model combines the medical and social model. Disability is an outcome of the interaction between a health condition and the environment, leading to impairment, limitation, or restriction (Fig. 1). It incorporates conceptual factors, which include environmental factors that one experiences on an individual and societal level, and personal factors beyond a person’s health, such as age, race, gender, and more (WHO, 2001). The purpose of the ICF is to standardize conceptualizations of disability worldwide to allow for better data collection. One tool derived from this model is the short set of Washington Group questions. These questions identify disability by focusing on impairments in "seeing, hearing, walking, cognition, self-care, and communication" ("The Washington," n.d.). There have been critiques regarding these questions because they focus primarily on functional limitations and do not explicitly identify individuals with psychosocial disabilities, albinism, and other conditions (*An Introduction, 2020*). In response to this, additional sets of questions have been introduced, and there is potential for further additions (*An Introduction, 2020*). Despite these limitations, countries are increasingly using this tool in census efforts to collect data on the prevalence of disability. For instance, Malawi used the Washington Group questions and included additional ones to specifically identify albinism and epilepsy in the 2018 Population and Housing Census Report (GoM, 2019).

While the ICF model can capture many aspects that affect one's ability, several concerns exist. Some critiques of the ICF model are pushing for more emphasis on the role of socioeconomic determinants of health and consideration for an individual's well-being (Mitra & Shakespeare, 2019). Although these personal and environmental factors are influenced by and influence health conditions, in the diagram, it appears that environmental factors and personal factors are not connected to health conditions (Fig. 1). Another criticism is that when the ICF model is practiced in policies, it needs to be clear that it "is not neutral, it is normative as it requires selecting relevant dimensions or aspects of lives" (Mitra & Shakespeare, 2019, pg. 339). As a result, there will need to be thresholds for these factors to determine what is considered to be a disability, especially to account for different cultural contexts. If countries are to use the ICF model, they should account for these limitations to best domesticate it to their local situation.

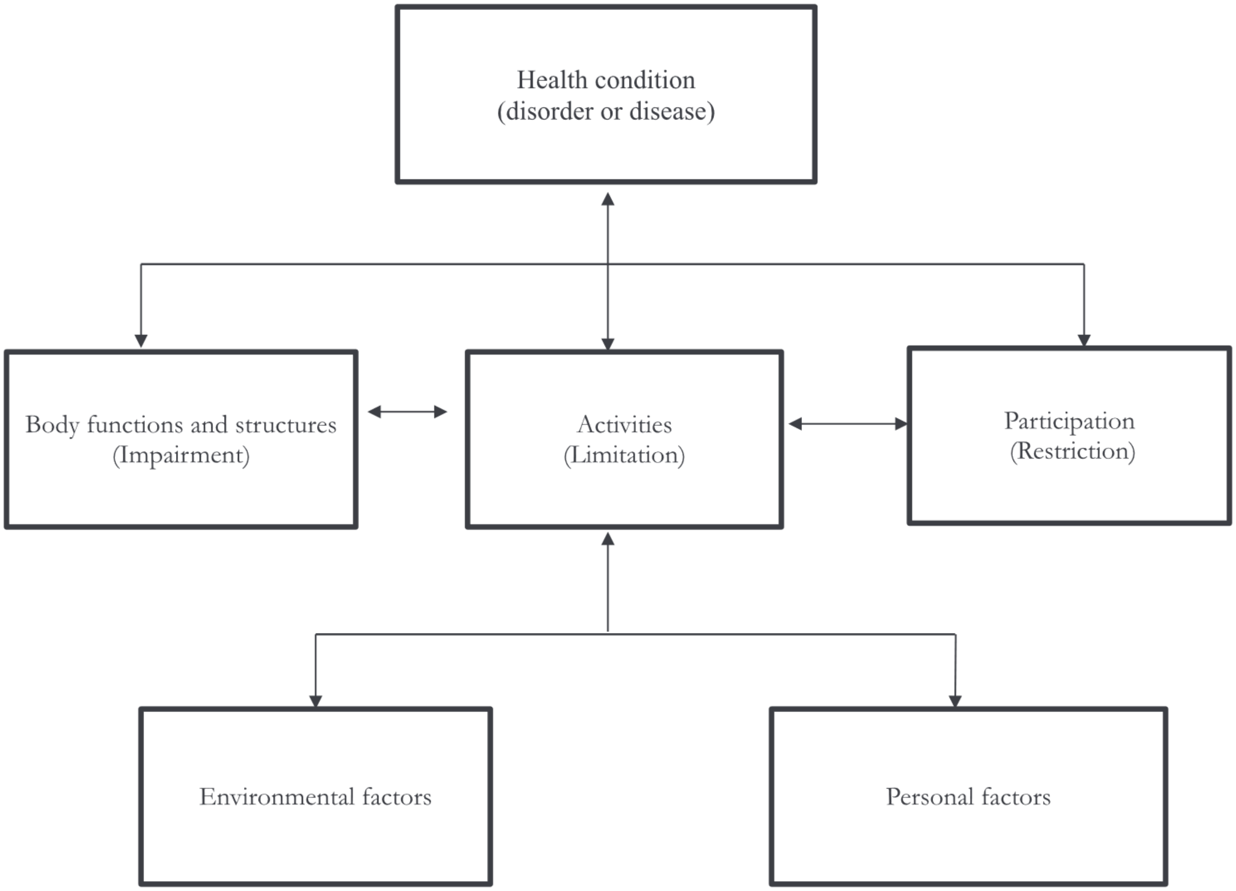

Figure 1. Mitra and Shakespeare (2019) adapted the ICF model from the World Health Organization.

With the CRPD's significant influence on national policies, it is essential to understand the disability models that have shaped it and any weaknesses it may have in addressing cultural contexts, especially in Africa. The last three models–social, human rights, and ICF–are embedded in the CRPD: the social model focusing on including people with disabilities, the human rights model on protecting their dignity and freedoms, and the ICF model defining disability. Despite the CRPD's inclusivity, during the negotiations for its development, issues unique to Africa were raised and overlooked in the finalization of the instrument (Onazi, 2020). Global South countries debated Article 19—"Living independently and being included in the community" (United Nations, 2006). They were concerned with the implications of the wording, potentially separating people with disabilities from their families and disrupting cultural norms (Palmsiano, 2017). Although the CRPD addressed the relationship between poverty and disability, African countries were alarmed by how poverty could exacerbate continent-specific issues, such as HIV/AIDS, and affect people with disabilities in terms of their access to healthcare, education, and employment (Mureriwa, 2011).

To better address disability human rights in Africa, the African Union (2018)—comprising 55 member states—adopted the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (commonly known as the African Disability Protocol, or ADP) in 2018. The ADP promotes positive African values and highlights the need to protect people with disabilities against harmful traditional and cultural practices. For example, it explicitly mentions sections on the right to live in a community, rights for people with disabilities of all ages (children, youth, and older), and the responsibilities member states have to protect people with disabilities against practices such as ritual killings, abandonment, witchcraft, and more (African Union, 2018). With Malawi and other countries ratifying the ADP in the past year, 14 member states have ratified it thus far(Alexiou, 2024). The ADP needs 15 member states to ratify it to come into effect (Alexiou, 2024). Although the CRPD is broad enough to allow for international use, there are merits to tailoring disability frameworks to fit certain cultures better and meet people's needs.

In disability studies, there is growing interest in viewing disability through a more African-centric lens to adequately address the history of colonization and cultural diversity on the continent (Soldatic & Johnson, 2019). Falola and Hamel (2021) have critiqued the medical model for their bias towards perspectives from the Global North and the West. Through the violent acts of colonization and the spread of disease, the colonial governments medicalized and defined disability to their standards. For example, individuals who resisted and Indigenous religious leaders were labeled as having psychiatric disorders (Falola & Hamel, 2021). There has been a shift from some of these international disability models, with scholars acknowledging that pluralistic models may be more common in East African countries (Stone-MacDonald & Butera, 2012). This model uses local socio-cultural beliefs and values to define normal functioning. In the West, disability models tend to overemphasize individualism and individual rights (Haang'andu, 2019).

In some African collectivist societies, such as Bantus in the southern region of Africa, solidarity and family are prioritized (Haang'andu, 2019). As a result, disability models that integrate African ontology, such as kinship and reciprocity, may be more appropriate (Haang'andu, 2019). One philosophy is the Pan-African *ubuntu* (or *umunthu* in Malawi) which describes how “one is not considered a human being unless one is concerned about the well-being of other people” (Falola & Hamel, 2021, pg. 22-23). In terms of disability, this view emphasizes interdependence and the social construct of disability within African communities (Falola & Hamel, 2021). Although *ubuntu* values caring for the sick and donating, it differs from charity or a choice because it is an ethical obligation to value lives and human dignity (Chuwa, 2014). In Malawi, *umunthu* may shape how health workers carry out mental health interventions, and leaning into these traditional Indigenous values can be more effective than Western biomedical values (Wright & Jayawickrama, 2021). With these vast arrays of disability models, it is important to study if they fully represent variation in people’s history and needs.

Another factor to consider is the complexity and nuances in the perception of abilities and disabilities in African countries. In many East African languages, there is no direct translation for the English term ‘disabled’ (Ogechi & Ruto, 2002). Instead, disabilities are often framed to specific body parts, making it challenging to classify disabilities together as a whole (Stone-MacDonald & Butera, 2012). The definition of disability can vary among countries, notably shaped by one's functional capabilities in daily tasks, which differ from higher-income countries in the Global North (Stone-MacDonald & Butera, 2012). For instance, someone with a physical impairment affecting their ability to walk and carry water might be considered to have a disability, while a person with dyslexia might not (Stone-MacDonald & Butera, 2012). In specific African communities like the Abagusii and Nandi in Kenya, disability is viewed through an individual’s abilities in cultural activities and adherence to social expectations rather than only on impairments (Ogechi & Ruto, 2002). For example, a physically impaired woman who is married and has children might not be perceived as disabled and may be more accepted than an infertile woman (Gbodossou, 1999). Given these diverse perspectives on abilities and disabilities, there needs to be more attention when examining disabilities within the context of Malawi and its policies.

Livelihoods and Education in Malawi for People with Disabilities

The majority of Malawians live in rural areas, accounting for 84% of the population. (McBride & Moucheraud, 2022). Among people with disabilities above the age of five, 10.6% live in urban areas, and the remaining 89.4% live in rural areas (GoM, 2019). Farming is the predominant livelihood option for Malawians, even in urban areas (Mkandawire et al., 2023) and for people with disabilities (Eide & Munthali, 2018). Urban centers, including the four main cities—Lilongwe, Blantyre, Mzuzu, and Zomba—and secondary cities (townships and district centers) offer additional non-agricultural livelihood opportunities such as finance and manufacturing (McBride & Moucheraud, 2022). However, people with disabilities are less likely to find formal salaried employment compared to those without disabilities, often relying more on subsistence farming, and they face a higher unemployment rate of 58% compared to 53% for people without disabilities (Eide & Munthali, 2018).

People with disabilities often face challenges with finding employment due to a lack of skills, opportunities, and transportation (International Labor Organization, 2007). Discrimination and accessibility issues are present throughout the application process and in workplaces, such as challenges with online applications for the visually impaired, phone interviews for those with hearing impairments, and structural barriers for people with limited mobility (Eide & Munthali, 2018). People seek vocational skills to find employment or start a business, but some individuals with disabilities find that specific training programs are inadequate in teaching marketable skills, inaccessible due to issues related to time and distance (Remnant et al., 2022), and have expensive training fees (Eide & Munthali, 2018). Unfortunately, employment challenges are linked to limited access to education, a barrier that people with disabilities continue to face (Wånggren et al., 2022).

In general, children with disabilities are less likely to attend school compared to their peers, with 25.4% having never attended school versus 12.7% of children without disabilities (Eide & Munthali, 2018). Banks et al. (2022) found that poverty was a major challenge for Malawian children in rural areas that affected school attendance. Although primary schools in Malawi were free, secondary schools required fees, which prevented many students from continuing due to the lack of affordability. Transportation was also difficult since it could be expensive, especially with most secondary schools being in urban areas. Another barrier was attitudes from peers who would bully and discriminate against individuals with disabilities. As a result, many were socially excluded and had low self-esteem (Banks et al., 2022). With these factors, it is unsurprising that children with disabilities in urban areas are more likely to have attended school for more years than those in rural areas (Eide & Munthali, 2018).

Health Access in Malawi for People with Disabilities

In Malawi, like many other countries, health access is intertwined with rurality, poverty, and disability. Rural areas tend to be deficient in health access because the cost of transportation and services is too high. The Ministry of Health in Malawi has a policy to have people live within an eight km radius of a health center. However, many fail to meet this (Munthali et al., 2017). Additionally, due to the government's limited budget and capacity for access, they have a system where services are provided by the Ministry of Health and the Christian Health Association of Malawi (CHAM), a partnered organization (Munthali et al., 2017). Unlike the Ministry, CHAM charges patients a fee and serves mainly the rural population, who are often living in poverty (Munthali et al., 2017). Poverty is crippling in all aspects of living, especially for people living in rural areas and/or with disabilities. There is an estimate that 80% of people with disabilities live in developing countries and are often impoverished (Brolan, 2016). Disability is also recognized as having a two-way relationship with poverty, where disability causes poverty and vice versa (Brolan, 2016). With a combination of these factors, health access is extremely challenging. In rural Malawi, some common health access barriers for people with disabilities include cost (transport, health passport, drugs), insufficient health care resources (lack of drugs, personnel, diagnostic testing/specialized treatment), dependence on others (for financial support, transport, for assistance in communicating), attitudinal barriers (towards the need for healthcare and the attitudes toward disabilities), and lack of time (Harrison et al., 2020).

People with albinism in Malawi also face similar challenges in accessing health care, especially in rural areas. Oculocutaneous albinism, commonly known as albinism, is a genetic condition that inhibits melanin (color pigment) production in the hair, eyes, and body (Franklin et al., 2018). Due to the lack of melanin, people with albinism face several issues with discrimination and health (Hong et al., 2006). For health issues, people with albinism are sensitive to ultraviolet radiation from sunlight, have a higher risk for diseases and skin cancer, and have low vision challenges (Franklin et al., 2018). According to the 2018 Malawi Population Housing Census Report, there are 134,636 people above the age of five with albinism, and they represent 0.8% of the population with disabilities (GoM, 2019). In Malawi, people with albinism face several issues, such as discrimination and violence due to cultural beliefs. Since 2014, the United Nations Human Rights Council has reported 150 cases of killings and human rights violations in Malawi (OHCHR, 2019). Many of these attacks are driven by superstitious and witchcraft beliefs about the ability of body parts from people with albinism to grant wealth and luck to the holder (OHCHR, 2016). Regarding health access, local health centers often lack medication and sunscreen, forcing them to go to the hospital in the city or purchase them from expensive pharmacies (Tambala-Kaliati et al., 2021). Some may even opt for cheaper sunscreen that is less effective. Unfortunately, some people with albinism learn about how to apply sunscreen too late, and it then becomes ineffective for damaged skin. Traveling to health facilities can also be costly, especially since only certain ones located in cities provide skin cancer screening. For people with albinism, economic constraints exacerbate health access issues. With the majority of Malawians being farmers, people with albinism are unable to withstand the harsh sunlight with their sensitive skin and farm for income and food security. They either need to work during early hours or find another job, which can be difficult when many employers believe that people with albinism cannot work (Tambala-Kaliati et al., 2021). Unfortunately, while Malawi's disability documents have enshrined the right to health for people with disabilities, access to health continues to be a difficult challenge.

Disability Policies in Malawi and other African Countries

In Malawi, numerous policies domesticate the CRPD to align with UN standards. Rotenberg et al. conducted a policy analysis in sub-Saharan Africa and found that out of 48 countries, Malawi had the most documents, totaling eight (2024). These include the Disability Act of 2012, the National Policy on Equalization of Opportunities for People with Disabilities of 2006, and the National Disability Mainstreaming Strategy and Implementation Plan (NDMS&IP) for 2018-2023 (Rotenberg et al., 2024). Since disability is a cross-cutting issue, multiple sectors and national documents mention it, such as the National Health Policy of 2018-2030, the Constitution of the Republic of Malawi of 1994, and the Malawi Growth and Development Strategy (MGDS) III 2018-2022. These documents emphasize and protect the rights of people with disabilities, but to have effective policies, they must also be well-known and implemented. Thus, this section focuses more on implementing disability policies in Malawi and other African countries.

Despite the many policies in Malawi, studies found a gap between employment policy and practice in informalized work settings for people with disabilities in urban areas (Remnant et al., 2022). Government officials were aware of the lack of impact the policies had on the ground, and trade unions had difficulties following policies. Despite employment policies being based on the social model, the working environment was still inadequate as workers with disabilities continued to face issues with employment and discrimination (Wånggren et al., 2022). It demonstrates that disability framings from the Global North are unable to capture the cultural and structural nuances related to disability and the economy (Wånggren et al., 2022).

Similarly, there is a lack of studies and follow-up on the impact of the National Disability Mainstreaming Strategy and Implementation Plan (NDMS&IP) for 2018-2023. It is the most recent disability plan for Malawi, and it has priority areas in access to health, education, livelihoods, empowerment, representation, and other issues. For the health sector, it stresses the importance of training health workers and mentions specific training in sign language, understanding disability, sunscreen protection methods, and more (GoM, 2018). The plan also has several strategy goals to sensitize various groups about disability, such as the public, family, and communities with people with albinism, parliament, and more (GoM, 2018). By including a comprehensive budget breakdown and evaluation plan, it stands out from other strategies across sub-Saharan African countries (Rotenberg et al., 2024). However, there are criticisms about the lack of equity and inclusivity. While many stakeholders developed the plan, it did not include enough people with disabilities (Ebuenyi et al., 2021). Policy makers need to take intentional measures to collaborate with marginalized groups to create more comprehensive policies and prevent exclusion (Huss & MacLachlan, 2016).

Like Malawi's National Disability Framework, South Africa has the Framework and Strategy for Disability and Rehabilitation Services for 2015-2022. Hussein El Kout et al. (2022) found that for policy implementers, there was an increase in awareness of services for people with disabilities but a lack of resources to realize them fully. For example, there was no dedicated budget to prioritize early interventions and personnel implementing the framework. Another concern was the lack of documentation on implementing policies and proper methods to monitor and evaluate the framework (Hussein El Kout et al., 2022). In Namibia, there are four main policies related to disability. Shumba and Moodley (2018) found that stakeholders involved in policy implementation generally knew about policies like the national one but fell short of other important ones. Other challenges included staff shortages and supply chain and distribution issues. Like in South Africa, there is still a lack of accessibility for people with disabilities in health services and a need for better policy enforcement in Namibia (Shumba and Moodley, 2018). These perspectives on disability implementation from countries in the southern African region provide insights into the challenges that may also be occurring in Malawi.

Study Sites/Locations

Malawi is a southeastern African country with a population of 17.5 million people (GoM, 2019). Due to convenience, this research takes place in two districts in the central region, Lilongwe and Ntcheu (Fig. 2). As a district, Lilongwe has urban areas, such as the capital, and rural areas. Similarly, Ntcheu has a peri-urban area where a major town is located and is surrounded by rural villages. In the central region, there are 6,434,150 individuals above the age of five with disabilities, constituting 43% of the country’s population of people with disabilities (GoM, 2019).

Figure 2. Map of districts in Malawi (d-maps.com, n.d.). The study locations, Lilongwe and Ntcheu, are labeled with a star.

This research focuses on various actors involved with disability policy development and implementation. On the national level, the Department of Disability within the Ministry of Gender, Community Development, and Social Welfare spearheads disability mainstreaming. The Ministry of Health tailors health policies to include patients with disabilities. There are also several organizations relating to disabilities that are either government or non-government affiliated. The Malawi Council for Disability Affairs (MACODA), formerly known as Malawi Council for the Handicapped (MACOHA), implements government policies for people with disabilities by providing welfare and rehabilitation services for all types of disabilities. MACODA offers training programs and has two vocational training centers to empower people with disabilities and prepare them for the workforce (United Nations, 2019). The Malawi Human Rights Commission (MHRC) is an institution that promotes and protects human rights (Malawi Human Rights, n.d). Although the MHRC has no legislative or judicial power, it is responsible for investigating human rights violations, and it has a role in promoting awareness of human rights and disabilities in the country, hosting training for government officials, and reviewing government policies (United Nations, 2019).

The Federation of Disability Organizations in Malawi (FEDOMA) and the Association of Persons with Albinism in Malawi (APAM) are two non-government organizations of persons with disabilities (OPDs) experienced in policy development and implementation. FEDOMA is an umbrella OPD that is the foundation of the disability movement in Malawi and comprises 12 OPDs. As an organization, FEDOMA is responsible for advocating and lobbying for equal rights and opportunities for people with disabilities according to UN standards. APAM is an OPD under FEDOMA that advocates and protects the rights of people with albinism in Malawi. They conduct sensitization campaigns to educate the public and empower and influence policies for people with albinism (FEDOMA, n.d.).

Health workers are the main policy implementers in the health sector as they interact and provide care to all patients. This research was conducted at several health facilities to get a variety of perspectives, including: Bwaila Hospital (urban Lilongwe), Ntcheu District Hospital (peri-urban), Kabudula Community Hospital (rural Lilongwe), and Gowa Health Center (rural Ntcheu). The Ministry of Health operate all health facilities, except for Gowa Health Center, a CHAM facility.

Researcher's Positionality

I am an Asian American woman who grew up and received an education in the United States. I have undergraduate training in biology and environmental studies with experience in quantitative research. In my studies, I have briefly learned about disability studies and read from scholars about their perspectives about having a disability. I have an immediate family member who has a disability. He has shaped how I see disabilities, especially recognizing the kinds of support that people with disabilities need. As I hope to pursue medicine, I am passionate about ensuring that health care is accessible to everyone. I know that people with disabilities and other marginalized groups and identities have more challenges accessing proper health care. This has translated into my research interest in exploring the intersections between disability, health, policy, and more. I have previous experience living in Malawi for one month, where I had the opportunity to learn more about the country, culture, customs, and healthcare system. During this period, I saw a person with a disability living in a rural area, which gave me the motivation to pursue this topic. Although I do not speak Chichewa, one of the local languages, I spent six weeks immersing myself in the country, taking classes at a local university, and interacting with people before starting data collection. These experiences and my time working at a local NGO, REACH Trust, over the summer have helped me stay engaged and better understand the community around me as I pursued my research.

Methodology

A qualitative study was conducted to assess the understanding of disability and perspectives on creating and implementing disability-related policies in government officials, disability-related organizations, and health workers in various geographical areas in Lilongwe and Ntcheu, Malawi. The semi-structured interview methodology was adapted from Marshall et al. (2022) to allow for standardized and follow-up questions. The interview questions and protocol for this study were approved by the Institutional Review Board at SIT Graduate Institute (Application No: 0000244) and the National Committee on Research in the Social Sciences and Humanities in Malawi (Ref No: NCST/RTT/2/6 and Protocol No. P.03/24/852). Interview questions were translated into Chichewa and back translated by a Malawian research partner to ensure accuracy. There were two sets of interview questions, one for government officials and disability-related representatives and the other for health workers. All individuals were surveyed on how they defined disability, the causes and types of disabilities they knew, how Malawians with disabilities were perceived, and any differences between having a disability in an urban and rural area. Then, depending on the participant's role, they were asked more tailored questions (see Appendix A). Government officials and disability-related organization representatives provided formal insight on disability policy creation and implementation, such as adaptation to international standards and challenges. Health workers in rural, peri-urban, and urban areas offered insight into the quality and type of care provided to patients with disabilities and the knowledge of disability-related policies and implementation in their health facility.

Interviewees were presented with paper copies of the consent forms (see Appendix B and C) to read and sign. One copy was given to the participant to keep, and the other copy was given to the researcher. With the assistance of a local Malawian interpreter, data was collected through one-hour semi-structured interviews conducted in either English, Chichewa, or a combination, based on the participant’s preference. During the interview, notes and an audio recording were taken with the participant’s permission to obtain accurate responses for data analysis.

Sampling

To identify participants, the Research for Equity and Community Health (REACH) Trust, a non-governmental organization dedicated to health equity research for marginalized communities in Malawi, provided assistance. We used purposive and snowball sampling to contact potential participants via phone or on-site. After we shared the study's details, individuals were given the option to participate in the interview. Interviews were conducted in person at the participant’s preferred location, such as a quiet room, an office, or a bench outside the health facility.

A total of 29 individuals participated in the study (Table 1). There were 15 male participants and 14 female participants. Four government officials were interviewed, including one representative from the Ministry of Health and three from the Ministry of Gender, Community Development, and Social Welfare—two in the Department of Disability and the Elderly and one in the Department of Social Welfare. For seven disability-related organization representatives, one individual was recruited from APAM and two individuals each from FEDOMA, MACODA, and MHRC. For a total of 18 health workers (six urban, six peri-urban, and six rural), there were six participants from Bwaila Hospital (urban Lilongwe), three from Kabudula Community Hospital (rural Lilongwe), six from Ntcheu District Hospital (peri-urban), and three from Gowa Catchment Health Center (rural Ntcheu). To capture a diverse group of health workers, a variety of roles—including clinicians, nurses, and health surveillance assistants (HSAs)—were selected from each health facility, aiming for one or two representatives from each role. The participants also represented a range of departments (Table 2). By coincidence, among the 29 participants, five had a disability: three representatives from disability-related organizations with albinism, one additional representative, and one health worker with a physical disability.

	M	F	Location	Govt/ Private	Type
Ministry of Health	1	0	Urban	Govt	Government
Department of Disability	1	1	Urban	Govt	Government
Department of Social Welfare	1	0	Urban	Govt	Government
MHRC	1	1	Urban	Govt	Disability-related organization
MACODA	1	1	Urban	Govt	Disability-related organization
FEDOMA	1	1	Urban	Private	Disability-related organization
APAM	1	0	Urban	Private	Disability-related organization
Bwaila Hospital	3	3	Urban	Govt	Health facility
Ntcheu District Hospital	2	4	Peri-urban	Govt	Health facility
Gowa Health Center	1	2	Rural	Mixed	Health facility
Kabudula Community Hospital	2	1	Rural	Govt	Health facility

Table 1. Research participants (n=29) were categorized by sex, location, government/private, and type of affiliation. There was a total of 15 male and 14 female participants.

	Number of health workers
Maternity/Midwife	6

General	5
Under five clinic	3
Tuberculosis	2
Hygiene & Sanitation	1
Trauma	1

Table 2. Distribution of health worker participants with their respective departments.

Data Analysis

Interview recordings and notes were transcribed and thematically analyzed, guided by steps from Thompson (2022) and Marshall et al. (2022). Transcripts were coded based on themes from the literature, such as disability models, health access challenges, international disability standards, and Malawian policies. Additionally, transcripts were coded to identify any similarities and differences between interviews, especially among their participant role as government officials, disability-related organization representatives, or health workers. Health workers were categorized by their roles and respective geographical regions. Codes were condensed into three themes: disability understandings, disability policy making and implementation, and disability policy in a healthcare setting. Sub-themes were identified to highlight patterns and trends between participants. The overall findings, supplemented by direct quotes, were organized into the report.

Findings

Understandings of Disability

Definitions of Disability

Government officials and disability-related organization representatives viewed disability through both the social model and the ICF model. Government officials generally understood disability to be a negative or restrictive interaction between an impairment and a barrier, which could be attitudinal, institutional, or environmental. One individual specifically preferred the definition of disability from the CRPD because of its emphasis on interactions. The majority of disability-related organization representatives saw disability as a limitation due to an impairment, preventing one from participating in daily activities or doing tasks that other people without disabilities were able to do. Similar to the government officials, one participant stated that disability arose from structural limitations, where “the problem is also compounded by what is within their locations or their environment” (P6). Both groups of participants separated impairment from disability and emphasized that there needed to be a restriction involved for it to be considered a disability. A representative from MACODA summarized, “The impairment is limiting that person to do activities. That’s when we say it's a disability. But we cannot take an impairment as a disability. They are two different things” (P7).

On the other hand, 12 out of 18 (66%) health workers, four from each geographical region, saw disability through a medical model framing. They defined disability as a physical attribute where a person lacked a body part or had a deformity. When directly asked, “What is disability?” many started referring to examples of physical disabilities, such as lacking a limb or being unable to walk, see, speak, or hear, rather than defining it in general. The other six health workers defined disability as an impairment that prevented someone from being able to carry out daily tasks and complete their duties. Two urban nurses specifically identified disability to include mental impairments.

Causes and Types

All individuals were able to give causes of disabilities. Participants understood disability to be congenital due to genetics or acquired through common causes such as road accidents, diseases, lack of timely medical treatment, and hypoxia. When asked if there was a connection between disability and old age, all government officials and disability-related organization representatives said “yes,” and that old age could eventually lead to someone developing a disability. For health workers, nine out of the 14 (64%) health workers who were asked also said that there was a connection between old age and disability. HSAs were more likely to say “there’s no connection” than nurses and clinicians. For the five individuals across all three geographical regions who did not see the connection, they explained that they saw old age as a “normal” and “natural process” that everyone would experience. One peri-urban HSA said there was no connection because “As we grow, we become old. So when somebody’s old, their body is becoming weaker and weaker. So, they may be unable to work or walk the way they used to be just because of old age” (P18). Similarly, the other health workers rationalized that older people would have difficulties with functional activities but did not recognize issues with mobility as a disability because it was only age-related.

As for the types of disabilities, all individuals except for one peri-urban HSA were able to free list examples of disabilities (Fig. 3). Two main groups of disabilities were identified: physical (n=10) and mental (n=10). Participants named physical disabilities such as visual (n=14) and hearing (n=11) impairments the most. Government officials, disability organization representatives, and some health workers knew more specific disabilities such as dementia, autism, cerebral palsy, and epilepsy.

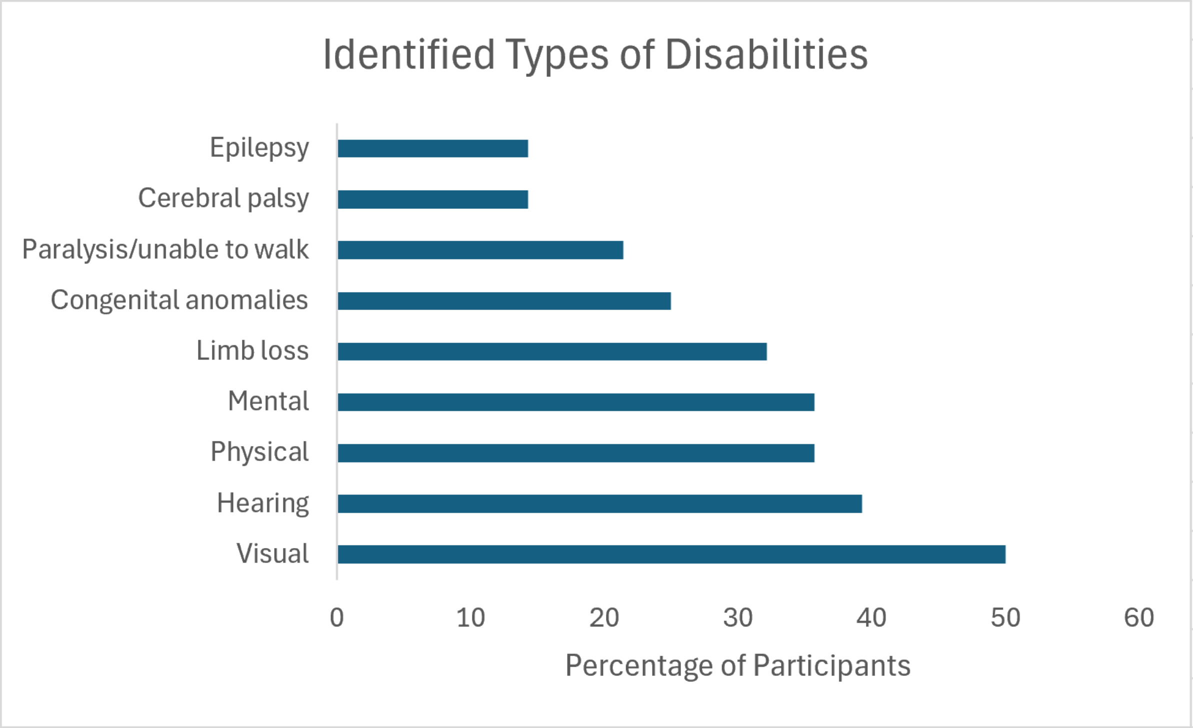

Figure 3. Percentages of participants (n=28) identifying examples of various disabilities. One participant was unable to provide examples and omitted.

In terms of albinism, all government officials and disability-related organization representatives stated that it was a disability due to the visual impairments, discrimination, and skin sensitivities people with albinism faced. On the other hand, 13 out of 17 (76%) health workers considered albinism to be a disability and gave similar reasons as to why. Initially, one urban nurse stated that albinism was not a disability, believing it only to be a difference in melanin levels without associated physical, mental, or intellectual impairments. However, she later reconsidered after recalling news from the radio about albinism as a disability and the past incidents of ritual killings targeting individuals with albinism. She also acknowledged the discrimination and lack of knowledge surrounding albinism by sharing an anecdote:

> I once came across an issue where a mother gave birth to an albino child. And then the family, actually the father, said the child should not go to his house because according to them, they understand that is a taboo. If the mother gave birth to an albino child, there must be something that she did that has led to her giving birth to that kind of a child. And we had to even try counseling the father in the family, but still, they did not understand (P17).

The four individuals who did not consider albinism to be a disability had various reasons. One peri-urban HSA explained, “Because they are normal people like us, just different in color, skin color” (P18). These health workers acknowledged the difference in melanin but mainly saw them as people who could still work and go to school. One rural clinician considered albinism to be a disability if a person also had vision impairments. Another urban clinician mentioned that the issues people with albinism faced could be avoided or fixed, leading her not to perceive albinism as a disability. She explained:

> To me, it’s like, I just take them as any other human being. Because they can cook, they can do farming issues, they can do fields, they can do everything. They can work, they can go to school. So, the challenge is just, they complain about—if they just follow what they have been given, the rules to wear the hats and to use sunscreen, therefore they’re just quite okay, like any other human being. And they just complain about sight. So, I can also—I use these glasses because I also complain about the same sight. So, it doesn’t mean that it’s a challenge, because I can complain about the sight, and they also have the same issue of sight issues. So, to me I don't think it’s a disability (P23).

Perceptions of Having a Disability in Malawi

All participants were asked about their perceptions of what it meant to have a disability in Malawi and how people with disabilities were treated. The majority of participants perceived it as a “burden” and “really challenging” for people with disabilities due to difficulties in earning income, communicating, walking, and often having to rely on family for support. They also reported that people with disabilities faced significant stigma and discrimination from the community. However, there has been a noticeable shift in attitudes and awareness regarding disabilities. While there are still lingering beliefs associated with disabilities with curses or witchcraft, these are more prevalent in rural communities with lower education rates. As a result of sensitization and awareness campaigns, there has been more acceptance of people with disabilities.

Respect and Equality

In terms of perceptions regarding respect for people with disabilities, some participants believed it varied depending on the type of disability. Six health workers—four urban, one peri-urban, and one rural—commented on these varying levels of respect. One urban clinician noted that visible disabilities tended to receive more respect and stated, "Someone with a visible physical disability, like missing limbs, is treated better than someone with blindness because the impairment is more apparent" (P12). Additionally, she observed that a person unable to speak might be respected more than someone with limb loss, as they can walk and work. This was contrasted by an example provided by a rural HSA where a deaf individual would be ostracized by their peers due to a communication barrier (P29). One urban HSA highlighted that with physical disabilities, those affecting the arms were more likely to receive more respect than those involving the legs due to the continued ability to walk (P14). However, severe disabilities impacting mental functioning were seen to diminish respect. For instance, an urban nurse shared that children with cerebral palsy, who may experience difficulty speaking or drooling, were seen to face ridicule from other children (P14).

Due to societal expectations, many participants observed that respect for people with disabilities was heavily tied to their ability to work. A disability-related organization representative described that the relationship between respect and the expectation to work applied to everyone:

> Because everyone expects you to be doing something to make money if you have a disability, and that disability hinders you from doing what is seen as a typical job, then there’s a little bit of a lack of respect for you because you can’t. Even when you’re able-bodied and you can’t get a job, the respect levels go down significantly (P5).

The majority of participants observed how begging was a means of livelihood for people with disabilities for various reasons, especially in urban areas. People with disabilities could be found along the streets begging for money. Children with disabilities were even exploited by their parents to sit on the side of the street to ask for money. One urban health worker explained, “[Parents] can leave their kid at home and go and work, find something and support their kid, but they would rather like exploit their kid so that they find money” (P16).

Participants emphasized that the widespread prevalence of begging had created a societal narrative portraying people with disabilities as lazy and not working. One urban clinician stated, “Yeah, they’re seen as lazy because most individuals with disabilities, they are seen in the streets begging. Some people say they are lazy, so they rely on the handouts” (P13). This narrative, in turn, caused individuals with disabilities to internalize these perceptions. As a result, two main effects emerged: people with disabilities developed an expectation to receive assistance, and they began to believe they were incapable of contributing anything. A former disability-related organization representative with a physical disability said that these attitudes were “planted into people with disabilities” (P9), and it was a cycle where people with disabilities were incentivized to look down on themselves and beg for money. Similarly, an MHRC representative described the impacts of low esteem within the disability movement, providing the rationale for begging:

> There’s a lot of self-stigma within persons with disabilities, and actually what has now killed the disability movement is that bit because of poverty. I think the majority of people with disabilities have just opted to a survival model. And that survival model and

> our approach is for them to go back to that thinking of people should help me. 'Y'know, people should feel sorry for me.' Because the moment people feel sorry for me, it's easier to give you money. The moment you show that you are very independent, you will not benefit from those things (P6).

Nevertheless, many participants used the phrase, "disability is not inability," and highlighted the need for people with disabilities to be empowered and have a mindset change. One peri-urban health worker stressed that empowerment needed to come from everyone and that support also needed to come from resources, not just words (P16). In addition, MACODA representatives shared the importance of their training and education programs to teach skills to people with disabilities and enable them to start a business. Role models could be influential in providing hope and inspiration to people with disabilities to show that it was possible to generate an income without begging.

Concerning social standing, participants identified that individuals with disabilities could gain respect by being employed, educated, or if they had support from their families. Jobs such as police officers, nurses, and parliament members had high societal influence and power. They would be perceived as people who could contribute to society. One government official phrased it as, "I see that for persons with disabilities who have a certain level of standard of living, they command respect" (P2). Participants perceived people with disabilities who were educated as having more respect due to knowing their rights and being able to do something. One urban health worker elaborated on the conditional respect:

> Only those who at least they went to school, they have some papers, they're doing something, they want that respect, but the rest, people look at them as they're just 'useless.' I can use that word useless because that's what most of people say. He or she is useless, there's nothing we can do, so they can't be respected. they're doing something, they want that respect, but the rest, people look at them as they're just 'useless.' (P13).

Families also had a direct impact on how the individual with a disability would be treated. If the family had an affluent and educated background, community members would be more likely to be respectful. These families would also send their child with a disability to school, increasing the likelihood of them being employed. On the other hand, if a family was poor or disrespected their family member with a disability, community members would also have less respect for them.

Similar to respect, equality for people with disabilities was perceived to be conditional. Some participants believed that people with disabilities were seen as equals because they were able to hold powerful positions such as a government or being a traditional leader in the community. Therefore, they had all the same rights and were treated the same as everyone else. However, others acknowledged that although people with disabilities were able to find employment, they continued to encounter several barriers. One peri-urban health worker mentioned that a person might have lacked the qualifications and training because they did not attend school (P18). Challenges in finding employment are connected to a lack of education, which many people with disabilities experience. Additionally, another peri-urban health worker attributed this issue to the presence of uneducated families:

> Whenever the parents themselves are not educated, and they have children, but they are not helping them maybe to go to school. To them, they don’t know the values of going to school. So, that can be a challenge to say that the children will go to school because it now starts with the parents and parental guidance (P22).

Two disability-related organization representatives commented on the lack of accessible workplaces, especially for people who use wheelchairs or have difficulties using stairs. One described how it contributed to the discrimination a person faced when job seeking:

> They apply to that vacancy. They go for interviews. The moment [the interviewers] see that there is a person on a wheelchair, automatically that person has less chances of being picked. Even though the person has all the qualifications, all the certificates. But, the interviewers will think, ‘Can this one go upstairs? No, he can't.’ Automatically, [they are] disqualified (P8).

A couple of participants observed inconsistent treatment in different situations and summarized their perception as “people with disabilities are only equal on paper.” While they were acknowledged to have the same rights, in practice, their treatment was shaped by social factors and varying understandings of disability.

Urban vs Rural

Given that the majority of Malawians live in rural areas, participants were asked if they perceived any differences between having a disability in an urban area compared to a rural area. The responses touched on several areas, such as understandings of disability, access to education, health, and employment. Participants shared how, in rural areas, people were likely to have less exposure to information and education. As a result, some people held stigmatizing beliefs about people with disabilities being cursed or afflicted by witchcraft. This affected how they treated people with disabilities, leading to neglect and abuse. One MHRC representative commented on the impacts of neglect on a person with a disability:

> But if you also look at the other extreme in the rural sector where people just wake up and just see disability as very normal. And then there's a lot of negligence. You see people, they don't have access to all the assistive devices and support. There are some disabilities where you see that if you could have intervened early, it's not that you are removing the disability, but you could have provided more, improved their status, improved their mobility, improved their self-confidence but because it was neglected in the community, there wasn't that support (P6).

Frequently, discrimination and maltreatment came from family members first. A disability-related organization representative shared her experience on human rights violations:

> In the cities, we will find that people are more compliant with the law. However, in the villages where they’re not really being watched much, people abuse persons with disabilities. Lock them in a room all day because they don't want people to know they’re living with someone that has a disability, or they have a child that has a disability because it’s seen as something bad (P5).

An urban clinician shared a similar story about a child being kept indoors in a village near Blantyre (P13). These individuals believed the behavior stemmed from a lack of knowledge and that sensitization or counseling would be required to change their ways. Some participants shared how people in rural areas were able to access phones, TVs, and radios to obtain information about disability. However, this was not accessible to everyone as one rural health worker explained:

> It's like just a few [in rural areas] who have access to the radio. Maybe we don't have the radio, because due to the lack of electricity, and also the lack of money to buy batteries. We have difficulties to access information (P28).

In comparison, a wide dissemination of information and technology options allowed the public in urban areas to be more familiar with disability. Organizations like MACODA and FEDOMA that provided sensitization information used a variety of formats such as billboards, social media, and mobile media promoters. One rural health worker was aware of these urban strategies that were limited in the rural areas:

> Sometimes we have the people. They can announce using a vehicle, moving around the community in the urban areas. Well, they cannot do that [here]. We wait for the headman, I mean the village chief, to tell someone to announce. But, yeah, it’s different in that way. Roads are difficult to travel (P26).

In terms of education for people with disabilities, some highlighted the issues in accessibility, especially in rural areas. In general, one FEDOMA representative said, “Many schools in Malawi are not disability friendly. Classes are not disability inclusive. Even some teachers are not disability-friendly, not disability-inclusive at all” (P10). While there are disability-specific and inclusive schools like for the deaf and blind, one MACODA representative pointed out the lack of adequate teachers and capacity issues:

> When we send children with various disabilities to our primary schools, we don't have teachers that can manage those children. And when we say we have to send them to the

> special school, the schools are full. We can't send them because they don't have space for everyone. That means other children are left at home without going to school. Because in schools that are near to them, they don't have teachers who are specialized to teach them. And the special needs schools are filled up. There's no space (P7).

In rural areas, social and accessibility barriers were also prominent, as one rural health worker described:

> So, in the rural areas there is a lot of discrimination. Most of them may not even attend schools or may end up just staying at home and being insulted and even maybe murdered. While on the other side, they are able to go to schools with which can accommodate the disability (P25).

The same FEDOMA representative shared the existing attitudes towards education in rural areas:

> In most rural areas, they don't see the reason of sending that child to school. They see it as a burden to them. No, it's like you are troubling that person. Maybe the person [with a disability] needs to be carried in and out. So, because [the guardians] need to do some developmental activities, they see like that person [with a disability] is a burden to them because they might not [be able to] go to the farming fields. Instead, they need to carry the child to school (P10).

For health access, participants noted significant differences between urban and rural areas for people with and without disabilities. In rural areas, there were fewer health facilities, meaning they could be located very far away and required expensive transport. If people chose to walk to them, roads were often in poor condition or inaccessible, especially for people with walking difficulties. In some cases, the lack of accessibility could lead to people acquiring disabilities. A peri-urban nurse shared her experience working in a rural area and the lack of resources for ambulances:

> Maybe you have a maternity patient, and you want–you have assisted, and you want them to be referred here. You have seen that it's an emergency. But for the ambulance to be here and collect the patient 52 kilometers away and come back, already it's a complication because most of the patients who delay at home will say, 'Maybe this problem was fixed.' The moment you are receiving at the maternal facility, the situation is already bad. The moment you'll be making some arrangements to have your ambulance, they also make arrangements as a facility to release an ambulance. Everything becomes delayed. So, at the end maybe you bring nothing. Sometimes, it's the unborn baby dying. Sometimes, if it doesn't die, then maybe you will have asphyxia

> problems, or else maybe the mom will [have complications] because we have taken time, so those can be challenges (P22).

A few health workers shared how some individuals depended on their guardians to carry or go with them health facilities, which could be far and burdensome. One peri-urban specifically shared how responsibilities in rural areas could overshadow the needs of people with disabilities:

> Because they have a lot of things to do. So [they think], 'maybe I should go for the farming first, then I'll take this one to the hospital.' Or they just buy local medication for them to take without any proper medical advice (P23).

Other common challenges in the rural areas included a lack of proper specialists, equipment, and medication for people with disabilities.

For employment and livelihood opportunities, some participants pointed out how people with disabilities could experience advantages and disadvantages in either region depending on their abilities. Specialized skills were more necessary in urban areas than rural areas, and one government official stated:

> If they have a skill that should be able to earn them a living in the urban area, it means if they locate to the rural area, their skill will be redundant. So, those in the urban area have managed to earn a living if they have a competitive skill. That makes them different if they were to live in the rural area (P3).

However, she did point out how there were different responsibilities in an urban area, such as paying bills, which could come with challenges:

> In case they don't have means to pay those bills and in case they don't have skills that are sellable, or they have a sellable skill but it's not hired, or they are producing something and it's not bought they may not be able to market it as others are. That person might resort to begging so we've seen that tendency a lot (P3).

She noticed that she did not see begging in rural areas, which was also mentioned by another government official (P4) and an urban HSA. The urban HSA specified how begging was harder to do in rural areas than in urban areas:

> When you have a disability, you feel like you have the right to go on the streets and beg. But then when you're someone from the village, you tend to question yourself if it’s possible for you to go in town and start begging. And the question remaining is, ‘Who is going to help me if I go there when I start begging,’ or ‘Where will I be?’ (P15).

Unlike in urban areas, many participants believed that people with disabilities could farm as a means of livelihood to source food and income in rural areas. However, this would be dependent on the type of disability and the circumstances a person had. The APAM representative pointed out the limitations people with albinism like him would face with farming:

> For me, my skin is so prone to the sun. Like when I get direct exposure to the sun ray, I develop some blisters that later can turn into skin cancer. So, that means I cannot be working on the sun like other people do. Like I cannot go to a farm and do the farming for like the whole day when there is a scorching sun, and we get lesions that will turn into skin cancer (P11).

Similarly, an urban health worker mentioned that there needed to be compatibility between farming and the type of disability:

> Even though you can walk distances, if your job demands you to be someone who is farming, and you have hands that are not really functional, it’s very hard for you to execute that work. So, you're looking for the money, but then your disability gives you limitations (P14).

Some people with disabilities still have to find a way to farm to generate an income despite issues with mobility. One rural health worker knew a farmer who wasn’t able to walk and said, “But because his farming area is near his home, he is able to farm. But, he always crawls when he’s tilling the land on his farm” (P29). In some cases, people with disabilities had external support for farming, as one government worker recalled that people could go to Mulanje Vocational Training Centre for the Blind and learn skills to cultivate the land. In rural areas, the livelihood opportunities and support for people with disabilities can depend on their abilities and their community. One government official viewed that in rural areas, “everyone is for themselves," whereas another said, "In rural areas, they have more support because they have relatives that are there. They know there are challenges, they will be able to support them" (P4).

Disability Policy Making and Implementation in Malawi

Domestication of the CRPD

To meet the UN standards of disability detailed in the CRPD, government officials and disability-related organization representatives shared that the progress and process of policy domestication depended on several factors, including the context of Malawi and implementation on the ground. A government official from the Ministry of Health described domestication as "the process of coming up with our own, our own documentation, our own act, our own provisions, our own policies based on the UNCRPD provisions" (P1). One government official from the Department of Disability said, "We have not comprehensively domesticated [the CRPD]," and explained that for current disability policies and laws:

> There are some aspects which we are fully implementing as covered in the CRPD. There's some aspects which we have partially. Some aspects have not yet been done. Maybe we may not even domesticate them, depending on the nature and how they marry with our policy and legal environment as well (P2).

All government officials had similar sentiments about emphasizing the need to ensure that the international guidelines were aligned with the realities of Malawi. Another government official stated, "We have to marry the international standards and what is feasible in Malawi so that it's adequate for Malawi" (P4). One government official provided an example of how Malawi considered which parts of the CRPD to domesticate:

> Let's take the CRPD, for instance. Malawi, as a country, we have always believed in community and family support. So, if something prescribes or talks about issues of, for instance, institutions or institutionalization, that one will conflict with our norms. So, we will respect what the international says, but we believe in the family and community care support, so we'll make sure that anything to do with the interventions that are promoting family and community care we get them, but if anything to do with institutionalization,

> which is not in line with our laws, our norms, our beliefs, we may not necessarily adopt those (P2).

Two individuals focused on how domestication related to Malawi's economic status. One government representative acknowledged how the "Global North is quick to set the agenda," therefore the progress of domestication of the CRPD would look different in developing countries due to financial constraints:

> For the case of the UNCRPD, we have principles in there that we are totally, that we are totally adopting. There are some that we have modified so that we are being relevant to our communities and to our situation. Because we are floating at different speeds in terms of development. So we should understand if disability is a development issue, we cannot sail at the same pace. So some might be at the start like us, some might be in the middle, some might be way ahead, so we cannot get the way ahead as a standard. We can be inspired, yes, but we cannot be pushed because we have different factors that should propel our speed (P3).

Additionally, she commented, "So we appreciate that the advancements that have been made in the Global North are progressive, we do, but we also appreciate that not everything that is reality for the Global South is redundant or is unuseful" (P3). Another government official had similar opinions and highlighted the lack of resources in Malawi affecting the type of assistive devices available. Despite the CRPD not addressing financial differences, he believed that countries could overcome it through alternative ways and still provide for their people:

> I know the UNCRPD does not take [financial situations] into consideration. But as a country, for us to achieve [international standards], we have to devise our own means. Using the local available resources to address the same needs that someone in the UK is supposed to. I know the quality will be different, but at least the outcome should be the same. So, it does in a way favor the ones with higher, the countries which are rich. They are not considering the ones which are ultra-poor. So, the best way is, as we can, ourselves, we should devise a way of at least meeting those means at a low cost (P1).

A representative from MACODA used the same assistive device example to show that he believed that the CRPD was domesticated to Malawi, but the application was contingent on the resources available. He identified how other countries had mechanized wheelchairs, which were very rare in Malawi. Thus, to him, it meant that “[UN standards] can’t be adopted everywhere. We can’t take it as a wholesome thing from those UN convention meetings because it depends on the resources we have here” (P7).

One government official and the majority of disability-related organization representatives mainly judged the adaptation of UN disability standards based on their implementation. The government official identified that some aspects of the CRPD were domesticated through local instruments such as the National Disability Mainstreaming Strategy and Implementation Plan 2018-2023 and the Persons with Disabilities Act of 2024. Although he believed that the CRPD was not properly domesticated due to implementation challenges, he recognized that Malawi was making an effort and allocating resources. In terms of the progress of the domestication of the CRPD, he informed:

> I should say that implementation of the UN CRPD is moving well in Malawi. But we need more time. Yeah, literally, we need more time because there are other needs as well. We can't move from zero, even when we start in a car. We can't move from zero to 100 kilometers per hour. No way. Moving slowly, slowly, slowly. Sooner or later, we find that we are there (P1).

One MACODA representative stated that the UN policies were adapted to Malawi because the country pledged to the 1994 UNESCO’s Salamanca Statement to make education more inclusive for children with and without disabilities. She added that with new policies, “before we start implementing that policy, they orient us. So, to avoid misunderstanding, they have orientations so that we can do the right thing in the fields” (P8). In contrast, three disability-related organization representatives disagreed on the domestication of the CRPD in Malawi. One explained the lack of knowledge about the CRPD in policy implementers:

> I don't think [the CRPD] is properly domesticated here in Malawi. I said earlier that only a few people know about that. And even when it comes to reporting, reporting is supposed to get views from different stakeholders, which is not even done properly here

> in Malawi. So we have that challenge that even most of the [OPDs], they don't even know what the UNCRPD is (P11).

The other representative from FEDOMA described that international policies were not adapted to the country due to the lack of implementation and said, “Many organizations, even in the government departments, they just symbolize that they are doing good in terms of disability inclusion, but on the ground, very few things that are happening towards persons with disabilities” (P9). Another FEDOMA representative said that policies were “adapted on paper…but to implement now. It becomes a challenge” (P10).

International Standards and Malawian Policies Meeting the Needs of Malawians

With Malawian policies being influenced by the CRPD, government officials and disability-related organizations gave insight into whether the CRPD and the resulting domesticated policies adequately addressed the cultural context of Malawi and met the needs of people with disabilities. A representative from the MHRC touched on how there was a lack of cultural context in international standards:

> I think [international standards of disability] were made without [cultural context] in mind. So, there wasn't really the concept of cultural relativism, which is the case with most models that are used in the human rights sphere. Because human rights are seen from a perspective of universalism, to say everybody should have equal rights and everything should be the same for everybody. So, because of that perspective, even these instruments will come with that. And so, it then becomes a localized thing to change the mindset so that everyone can then subscribe to what the principles are saying (P5).

Conversely, a government official appreciated how the vagueness of the CRPD allowed for flexibility and adaptability to each country’s cultural context:

> We have to accept disability based on our own understanding. That's why the way we define disability in Malawi can be different with how we define it in Zambia, our neighbors. That's the beauty about the CRPD. It did not specifically give boundaries. If we had given boundaries, they would have had problems, but it's very open, it's evolving. It can change with cultural, geographical, and even with time. The way we're understanding disability now is not how we understood it years ago. And if you are to go

> to local communities, when you just ask them about a person with a disability, they will bring in even those that are sick, that's their understanding (P2).

In terms of the CRPD and the policies based on the CRPD meeting the needs of Malawians, the majority of participants said they were only partially able. One MHRC representative said it would require more capacity building, but currently:

> I would say not really. They're more of guiding principles at the moment and not for enforcement. So the only amount of enforcement that would come out of them is to say we use them in like, legal battles. Use them as reference for our investigations and things of that sort (P5).

One MACODA stated that cultural differences played a factor in how well the CRPD met the needs of Malawians:

> I cannot say [UN models and conventions] completely meet the needs of Malawi because we have different cultures. Yeah. And because of different cultures, maybe different understandings, find that there are, maybe sometimes there are gaps. There are other policies, which can work well outside, but they cannot work well here. Yeah, we have to maybe adapt to a Malawi setting (P8).

Another MHRC representative highlighted how the CRPD lacked the cultural differences in countries, especially in Africa. He identified that the African Disability Protocol took a more focused approach to address them and emphasized the historical context of African countries to meet their needs:

> Yeah, so I think there are very specific cultural context issues that the CRPD missed. [The ADP] also has specific provisions for harmful practices and other things you are asking. Because those were not very clear in the CRPD. And even harmful practices, because of Europe, we are all colonized by Europe, they didn't bring in witchcraft or harmful practices as an issue. So, the African Disability Protocol has specific provisions and even definitions of what harmful practices are in the context of Africa and how that has contributed to mutilations, violation of human rights of persons with disabilities (P6).

He noted how Malawi recently ratified the ADP, and it would require more years to see the impact of it on Malawian policies and implementation. One government official acknowledged how the ADP addressed African issues, such as attacks on people with albinism. He described the ADP as “80% of it, it has taken things that are in the CRPD, but a little, 20% that has been brought in as new, as different from the CRPD” (P2). He believed that through proper domestication of the CRPD, “we should be able to address issues of persons with disabilities in an African way” (P2). He summarized his views on various disability frameworks as:

> So, there won't be an instrument which everybody will say it's all-encompassing, all is comprehensive, there will always be gaps. So, let's approach the CRPD as it is. We accept that it has some gaps. Let's look at the African Protocol as it is. It has also its gaps and weaknesses. Then let’s capitalize on its strengths and work on those to actually amend our policies and laws (P2).

Challenges in Policy Making

Regardless of how government officials and disability-related organizations felt about the CRPD and domestication, many recognized that a main challenge in policy making was related to a lack of capacity. One government official commented on a lack of personnel and budget in the Department of Disability. At the national level, there were only six officers in the department to serve the whole country. For the budget, he explained, “Some studies that have been conducted have shown that the budget for disability is 0.001, if I'm not mistaken, of the national budget (P2). In addition, he emphasized how the resources allocated to the department would now have to be shared among other departments within the Ministry. An APAM representative further elaborated on the demotion of the national disability sector from a ministry to a department, demonstrating the low priority for disability issues. Previously, it was part of the Ministry of Gender, Children, Disability, and Social Welfare. Now, it is incorporated under the Ministry of Gender, Community Development, and Social Welfare, which includes a Department of Disability.

Low capacity also contributed to bureaucratic issues and slowed down the policy-making process. Although disability was a cross-cutting issue, not all sectors equally included disability mainstreaming into its policies. One Department of Disability official shared that this was likely due to a lack of knowledge and how their department was responsible for addressing it:

> I think the issue is they now have is to know what the disability policy is, and how that informs their sector or the work that they are doing. So, the challenge comes in if they don't know, they will not be able to implement. So, our role as well in coming up with policies, we have also to build the capacity to promote mainstreaming, disability mainstreaming in those sectors or ministries, departments, and agencies (P2).

Another government official elaborated more on the difficulties of equal mainstreaming between sectors:

> Collaboration across sectors is also a problem. And sometimes we've had cases where policies are drawn, they are drafted, and they are adopted, and disability was left out. And so you wait for a whole cycle. Maybe on review, that's when you discover that disability is not there. So, it's not every sector that has gone through disability mainstreaming. Other sectors are still leaving disability behind, so those are some of the challenges, because if the sector leaves out disability it will not program for it, it will not plan for it, it will not finance it (P3).

Due to the lack of resources, the process of getting a policy passed and reviewed could be very time-consuming. A government official explained how once a policy or plan has been passed, “normally it’s supposed to be reviewed within the period of five years” (P1). However, one MHRC representative detailed the long process and how the five-year period is not always followed:

> All policies are championed by government, and then they have a standardized structure of how the policy will be done. So, that process is long. And then the likelihood of losing the momentum in that process is high because of competing priorities. And unfortunately, that's the political process now. So, if either the government of that time is interested in your issue, whether one person in that Ministry is interested in your issue, you see that it will move so fast. If none of the politicians are interested, then it will take ages for that document to be into a full policy. We have had issues whereby even our recent Persons with Disabilities Act of 2024. It has stayed in cabinet, like cabinet committee, for more than five years (P6).

One MHRC representative pointed out how the National Mainstreaming Strategy Plan 2018-2023 needed to be reviewed, but there were funding challenges:

> Yeah, so [the National Mainstreaming Strategy] needs review. And then we go back to funding, so there's no funding for the review. But it's been spoken of. And we have also written to the ministry to say we need this to be reviewed. And a new strategy to be made (P5).

Another challenge policy making participants identified was the lack of representation of people with disabilities. In addition to one government official, the four disability-related representatives with disabilities themselves mainly spoke out on this issue. One FEDOMA representative expressed his experience when asked to participate in a policy consultation to gain input from a person with a disability and described it as symbolic because the request for the consultation was made very suddenly and it was very brief. The APAM representative echoed how consultations were just a formality or even a requirement:

> The way I know Malawi, sometimes we conduct these consultations for the sake of conducting them, that the donor is asking us to do that. So, you go to the field when you already have everything written, even what the people say, you don't even include that (P11).

Another representative shared similarly disappointing consultation experiences from policy makers that had their own biases and did not include their input:

> Normally, if the government perceives that people who have disabilities themselves, they don't have the [technical] expertise. Then, they are labeled like they don't know what they want. So, it's like a certain group of people just draft the police without necessarily putting in the input and the voice of people with disabilities themselves. And then there are issues where we have seen, we did proper consultations as a disability movement. And then the policy makers, when they're doing the final draft, they remove them because they feel they are not very important (P6).

The other FEDOMA representative pointed out a lack of inclusion in the policy drafting consultations due to the lack of rural representation: “It's mostly symbolic because whenever they are making policies, maybe they might invite a person with a disability who is usually in the urban area. But that person who is in that deep rural place may not be involved. So, it becomes a challenge because that person is not even aware that there is a policy” (P10).

Challenges in Policy Implementation

While participants acknowledged the progress of disability issues in Malawi, they all identified the lack of capacity and resources to affect policy implementation, like with policy making. Some also noted poor attitudes among implementers. One government official described Malawi's overall policy situation:

> As a country, we have got good policies. And we make good, good policies. For example, we have got one that we did in 2020, the medical rehabilitation policy. But the main challenge in Malawi is the implementation. Literally speaking, it's the implementation. If all the policies were adequately implemented, I'm telling you, this would have been a better place for all (P1).

Another government official made a similar statement about the lack of implementation due to capacity issues, "We do not have capacitated interventions that can see to it that what we are providing for in the legal framework and what we are calling for in the policy is really adhered to, is really implemented" (P3). Three government officials and two disability-related organization representatives highlighted the lack of capacity at the district level, where most of the policy implementation is done. One MACODA representative emphasized how there were desk officers at the district council, "but that person is not trained in disability issues. It's just someone who's maybe trained in community development or social work, but not specifically for disability" (P7). An APAM representative commented on how the lack of capacity contributed to the lack of follow-up on the impact of the policy and stated:

> For example, the National Action Plan [for People with Albinism]. Yeah, it started from 2019 to 2022. But up to now, there is no follow-up report that said this is how the National Action Plan was implemented. And the next steps that will follow is just the document is just there. It was implemented but no one knows how the implementation was done (P11).

Four disability-related organization representatives focused on the lack of capacity in implementing policies in the health sector. There was a great need to ensure that language interpreters, assistive devices, and medications were available for people with disabilities. One MHRC representative shared:

> We found that most hospitals in the country don't have the right medication for specific mental illnesses or mental disabilities. So they end up improvising. So you have like one medication that they know will treat schizophrenia, and they'll give it to someone with dementia because they're similar. The symptoms are similar, so this should help (P5).

In addition to capacity, there were difficulties in the attitudes of policy implementers. An official from the Ministry of Health emphasized how implementers perceived that policies were not binding:

> And some, in the implementers, may choose not to [implement]. After all, this is a policy, it's not a law. It's there to guide, but it's not a legal thing. They can choose to neglect it. And then we find out the challenge that the policy is meant to address remains unaddressed (P1).

Similarly, another government official spoke on the attitudes of policy implementers:

> I think one of the biggest challenges are the attitudes. Attitudes among implementers, attitudes among the public. So, we have a very big task to actually change the mindset, the thinking of other policymakers, planners, implementers on how they perceive issues of disability. We are aware that others still perceive issues of disability as kind of welfare things (P2).

One FEDOMA representative spoke from her advocacy experience that there was resistance from policy implementers to carry out policies. They would claim to hear the concerns and implement policies, while in reality, very little or none of the policies were implemented. She speculated on the reasoning and explained, “Actually, they claim that they don't know that these people need these kind of services. But mostly, it's just negligence. They feel like doing something for a person with a disability will cost them a lot” (P10).

Disability Policies in the Health Sector

Knowledge and Implementation of Disability Policies

For health workers—the policy implementers in the health sector—eight out of 18 had a lack of knowledge on policies related to disability and if they were implemented at the health facility. Out of the remaining 10 health workers, five were able to identify that all patients, regardless of having a disability, had the right to access health services equally. Three health workers mentioned that there was a policy to prioritize treatment for people with disabilities. One urban clinician knew the 2006 National Policy on Equalization of Opportunities for Persons with Disabilities. Due to personal interests, a rural HSA knew that the Constitution included a section of people with disabilities that protected their rights. Three health workers–one peri-urban nurse and two from the same rural health facility–mentioned that the equal health access policy was implemented through improvements in the health facility infrastructure. At the rural Kabudula Community Health Center, there were ramps installed to increase mobility accessibility. At the peri-urban Ntcheu District Hospital, there was a specific toilet for people with wheelchairs.

Although some health workers did not mention prioritization of people with disabilities as a policy, 11 health workers mentioned that it was something that occurred at the health facility. One urban nurse explained, “They should be assisted first so that they can go [home]. That is our form of respect” (P16). Similarly, a rural HSA said, “We prioritize them because sometimes they need special attention” (P24). Two health workers, one peri-urban and one rural, specified that people who had trouble walking or were in a wheelchair were prioritized. One urban clinician shared an anecdote about an attempt to prioritize a person in a wheelchair:

> There was a time when a patient with a disability who came for [the outpatient department] was in a wheelchair. So the clinician said, ‘Let me start with him first, then we'll proceed.’ But then the guy was like, ‘Why do you start with me? I'm just like each and every one of the patients who are here, why starting with me? What have you noted in me?’ (P13).

Challenges in Implementing Policies

Some health workers reported challenges in giving equal care to patients with disabilities due to communication barriers and health worker attitudes shaped by lack of knowledge and exposure. All but three health workers stated that people with disabilities were treated the same as patients without disabilities at the health facility. Two nurses, one urban and one rural, said that health facilities tried, but one common challenge they faced was communication. It would be hard to treat patients if they could not hear and speak due to the facilities' lack of sign language interpreters. They recommended that patients come with their guardians to help assist with interpreting to ensure that health workers could give proper treatment. However, one rural nurse identified how difficult it was to have guardians accompany the patient and help interpret for them in rural areas because they would be busy with their daily duties. One urban HSA with a disability stated that patients with disabilities were not treated the same, and “in most cases, there is still stigmatization while they're trying to access that help” (P14).

Although the majority of health workers believed that patients with disabilities were treated equally at the health facility, 10 out of 14 also acknowledged how there were attitude differences among health workers. A health worker’s attitude towards a patient, especially with a disability, could impact the care they gave, as one urban nurse stated:

> I believe our work as health workers mostly depends on your attitude, how you view certain patients or a certain situation. So, if you have a negative attitude, definitely you're going to either provide the care or not. If you have a good attitude, positive attitude towards certain patients who are maybe with disabilities, you're going to give them the required care. So, I think attitude plays an important role in how one delivers care to the patient (P16).

Similarly, one urban clinician recalled hearing about a health worker receiving disciplinary action due to discrimination towards an older patient with disabilities by refusing to give them medication:

> One of the nurses was claiming that 'you know, this, we say, you're already old, 50 or 60s, at least you have done your part. Why should we give you this medication? We can give this to the younger ones, not you' (P13).

Health workers gave several reasons to explain the attitude difference, such as being overworked, not liking their jobs, and perceptions towards people with disabilities. Four health workers identified the main factor to be one's humanity or how one was raised, specifically referring to *umunthu*. One urban HSA described:

> It all comes down to humanity (*umunthu*), how you were raised. So, if you are someone who was raised in an environment where you're inconsiderate of other people's emotions, how their life is, it's very hard for you to show respect to someone who has a disability because you are raised in a way that you show no empathy to anyone. But then, if you are raised in a proper manner in a family that shows empathy to people, you are able to practice that, even at this health facility, because you know how positively that will affect the person with the disability when they come in here to receive help.

Another urban clinician believed that poor attitudes from certain health workers stemmed from ignorance:

> Because there's also the issue of knowledge gap. What the government is saying about people with disabilities, what I was supposed to do, the guidelines, the policy whatsoever. Because we don't know what it is all about in those guidelines and policies (P13).

When asked about receiving disability training, the majority had not received any. Only three health workers, all male clinicians, reported receiving some form of training on disability. A peri-urban clinician received training from the organization St. John of God on mental health associated with disabilities and learned which medications to give to patients. A rural clinician asked if albinism was considered a disability and explained how, as an intern, he attended a session hosted by two albinism-related organizations, BeyondSuncare and Standing Voice. He learned about albinism, the related myths, sun protection methods, and more. However, he did not recall albinism being talked about as a disability and did not consider it to be one. An urban clinician pointed out how, as a clinician, he received schooling on disability from only a biomedical perspective:

> In our training, like in medical training. We don't have a specific part; it's talking about how to manage people with disabilities from a physiology point of view. ‘When someone has this, this is a disability. When you're managing this, you do this, this, this, this.’ But it's not a specific topic of managing people with disabilities. So, it's just in general if we meet this, how you are going to deal with the problem, you do like this. But not necessarily in a way that is part of how to interact with those. No, it's not in the syllabus.

Additionally, he shared that he attended a meeting hosted by an organization, but disability and disability policies were briefly mentioned in two or three slides. For these meetings and training like these offered by organizations or the government, he expressed how they were very exclusive and said, “It's not for everyone. Those only who went for the meeting are the ones who benefit from it. And usually, it's not disseminated to the rest of the care providers” (P13). Two other health workers also shared this sentiment. Interestingly, one rural HSA had received no formal training on disability but knew more about disabilities due to his brother, who had albinism, and a friend who connected him to MACODA.

Another factor that affected knowledge of disabilities in health workers was the frequency of their interactions with patients with disabilities. For the group of participants, there was a wide range that often depended on the type of health worker and department one was in. HSAs were more likely to have frequent interactions with patients with disabilities in the community, sometimes even daily or weekly. However, one peri-urban HSA working in the under-five clinic said he rarely saw patients with disabilities because they typically went straight to the specialists. In the maternity department, urban health workers stated interactions were rare because “to find a woman who has a disability, is pregnant, it's once in a while” (P16). In addition, one urban clinician estimated seeing a patient with a disability once a month, despite “Bwaila [being] one of the busiest maternity hospitals here in Malawi” (P13). He believed it was on the lower side because “there are a lot who can't even access the services that we provide here, they're still in the villages” (P13). 7 health workers mentioned that some departments may have more patients with disabilities than others, such as the outpatient department, physiotherapy, dermatology, orthopedics, and labor ward.

Discussion

The landscape of disability and related policy making and implementation is nuanced in Malawi. From interviewing government officials, disability-related organizations, and health workers, they revealed that understandings and perceptions of disability in Malawi are influenced by Global North models of disabilities and various local factors such as type of disability, livelihood, and geographical region. National disability policies have made progress in domesticating the CRPD, but there are challenges due to the financial and local circumstances of Malawi. There also needs to be more attention to the cultural context of Africa as the CRPD fails to address them. Therefore, utilizing the African Disability Protocol may be more appropriate to meet the needs of Malawians. Disability policy implementation in general, has challenges with lack of capacity and poor attitudes from implementers. In the health sector, disability policies are not properly implemented due to the health workers' lack of policy knowledge and disability training, which has led to attitude differences affecting the kind of care they provide to patients. The following section will use literature to contextualize and delve deeper into the impacts of the respondents' views on disability, disability policy making, and implementation.

Perceptions of Disability

Understandings of disabilities varied between participants, and perceptions of disabilities in Malawi were defined by models from the Global North and local factors. Due to the difference in policy knowledge, there was a discrepancy between how government officials and disability-related organization representatives understood disability compared to health workers. Government officials and disability-related organization representatives were more familiarized with the social and ICF model of disability, whereas the majority of health workers saw disability through the medical model. These were the same findings that Braathen et al. (2015) saw in Malawian rural health workers in the professional and folk sector. Although one possible explanation could be due to language and interpretation of East African languages not having direct translation for ‘disabled’ (Ogechi & Ruto, 2002), it is unlikely because there is a Chichewa word for disability, *ulumali* (Mapira, 2024).

The more likely reason for the emphasis on the medical model is the lack of disability training. The National Mainstreaming Strategy and Implementation Plan 2018-2023 included a goal to provide ongoing training to certain health workers such as “physiotherapists, orthopedics, dermatologists and ophthalmologists” (pg. 39). None of the health workers interviewed work in this field, which could explain how the social or ICF model was not very widely known. Due to the lack of disability training, many health workers developed their understanding of disabilities based on their interactions with patients. Some health workers, such as HSAs who work directly in communities, reported treating patients with disabilities more frequently than nurses and clinicians.

For the few health workers who attended disability training and meetings or knew any peers who did, they mentioned how there was an issue with the dissemination of information. These trainings had a status attached to them and were seen as exclusive opportunities, so health workers would not share the information they learned with their peers, and there was resistance to learning secondhand information. D’Adamo et al. (2012) found similar patterns among health workers in India, Senegal, and Malawi, where meetings were the most common method of communication, and a top-down approach limited access to information and prevented knowledge sharing. In Ethiopia, health workers’ trust in each other’s knowledge and opportunities within the health facility to present information were the most significant factors in encouraging knowledge sharing (Dessie, 2017). Health facilities in Malawi should aim to implement a policy where health workers create a write-up of the information learned from training and present it during meetings.

Regardless of the type of health worker and the frequency of interactions with patients with disabilities, it is crucial for health workers to know about disability outside the biomedical context. Braathen et al. (2015) found that health workers who had medicalized disability failed to provide any rehabilitation information, where and how to seek help, and how to learn to live with a disability for a patient who developed a disability through illness. The lack of knowledge about the needs can also lead to downplaying patients' struggles and judgmental attitudes, which was observed when one clinician believed her vision issues were the same as people with albinism and could easily be fixed with glasses. Attitudes from health workers are also major health access barriers for patients with disabilities that even affect their decision to go to a health facility (Munthali et al., 2017). Some health workers mentioned that the poor attitude was a result of the lack of *umunthu,* humanity. This paralleled findings from Wright & Jayawickrama (2021), who saw that health workers who held *umunthu* values improved the type of care they gave.

In Malawi, perceptions of disabilities were affected by the type of disability, livelihoods, the charity model, and geographical factors. Some disabilities had different reputations due to their range of functionality, alluding to a disability 'hierarchy.' Physical disabilities such as limb loss were better received than mental, learning, or emotional ones. McCoy et al. (2012) saw that this was especially true for children in a school setting where children with learning and emotional disabilities were treated negatively and isolated more than children with physical disabilities. The visibility of a disability also plays a major role in perceptions, which can lead to positive or negative treatment. In a school setting, university students may perceive students with visible disabilities as more academically capable and sociable than their peers with hidden disabilities (Akin & Huang, 2019). It can affect employment opportunities if people with hidden disabilities choose to disclose their disability or not (Saal et al., 2014). The mobility of physical disabilities was another factor to consider as it could determine employment, favoring limb loss in arms over legs depending on the job.

One's ability to work was deeply tied to respect for people with disabilities. If they were seen to be begging in the streets in urban areas or not working, the public viewed them very poorly. It is a common phenomenon for disability perceived in the context of employment, where employment can decrease the negative attitudes around people with disabilities because they are perceived as productive members of society (LoBianco & Sheppard-Jones, 2007). This is likely why certain health workers did not view albinism as a disability because they believed they were able-bodied and could find a job. Certain jobs like a government worker or a nurse were seen to elevate the status of people with disabilities since they had authority in society.

The perception and stigma from the general public toward people with disabilities as being useless enables the charity model. It has led to low self-esteem among people with disabilities and increased reliance on begging for income, as formal employment often presents accessibility barriers. The pity and charity from others can also reinforce this behavior. Unfortunately, with the rise of urbanism, begging has even become more sought after as a livelihood for people with disabilities in African countries (Falola & Hamel, 2021). There needs to be more efforts towards educating and increasing awareness about disabilities for the general public. For people with disabilities, empowering them with vocational skills to allow them to work and live an independent life becomes even more vital.

The last factor mentioned by participants was geographical location, highlighting how a person with a disability experiences different perceptions and challenges in rural areas compared to urban settings. In rural areas, family and community members were more likely to lack knowledge about disabilities have beliefs about witchcraft due to poor access to information. As a result, they would discriminate, neglect, or even abuse people with disabilities. In South Africa, Booyens et al. (2015) found similar discriminatory attitudes from family and community members that stemmed from superstitious and cultural beliefs. In addition to negative perceptions, people with disabilities faced structural health access challenges such as distance to health facilities, costly transportation, or lack of someone to accompany them to the health facility. These barriers matched with what Munthali et al. (2017) found in four districts in Malawi. Some rural health workers mentioned how communication barriers were another factor that prevented patients who were deaf from accessing proper care and recommended that these patients come with a guardian to help interpret. However, having a third person could limit the privacy a person would have and prevent them from sharing some information with medical personnel (Munthali et al., 2017). In terms of livelihood opportunities, farming was the main option in rural areas, compared to urban areas where begging was a common reality. Without opportunities for specialized or formal jobs, finding a source of income in rural areas is heavily dependent on one’s mobility and support from their family.

Domestication of the CRPD and Implementation of Disability Policies

Through the CRPD, the Global North has affected disability policies in Malawi. There has been progress on domestication, as shown by the numerous legislation, policies, and plans around disability. However, the effectiveness of these policies is affected by a country's financial and cultural situation, dictating how well they can implement them. Although the CRPD is broad enough to allow for flexibility, the Global North largely shaped it. Countries in the Global South that are encouraged to follow these policies face a different reality that is often not acknowledged by wealthier nations. As a result, this can set them up for failure.

Grech et al. (2023) found other countries in the Global South—Kenya, Philippines, Jamaica, Guatemala, and South Africa—had similar challenges to Malawi in domesticating the CRPD, such as funding, lack of inclusion, and cultural differences. In the context of poverty, other issues, such as hunger, had a higher priority compared to the needs and rights of people with disabilities. Country representatives also stated how it was expensive to localize the CRPD. This parallelled perspectives from Malawian government officials who believed that the price tag was a main barrier to implementing disability policies. Among the countries in the Global South, some identified an urban bias in the disability policies that did not represent the experiences of people in rural regions. This urban-centrism was noticed in Malawian policy development as well. The last critique of the CRPD from the countries in the Global South was that the rights were seen to be individualized, which did not integrate well with more communal communities (Grech et al., 2023). Although Malawian government officials and disability-related organizations did not specifically mention individualism, Haang'andu (2019) does highlight this existing concern about disability models from the West.

Rather than placing the responsibility solely on the country to domesticate the CRPD, which might not be able to address all their needs, countries from the Global South should also model their policies after more localized frameworks. For African countries, the African Disability Protocol is one option to better contextualize disability to address the heightened stigmatization of people with disabilities on the continent. Onazi (2021) acknowledges how the ADP prohibits harmful cultural practices but argues that some aspects of it are still vague. Its views on poverty in Africa are not significantly different from the Convention. Therefore, he suggests that the ADP should be used alongside the CRPD instead (Onazi, 2021). This complementary approach could be an ideal middle ground, as the CRPD has encouraged many countries to make strides in protecting disability rights. Its weaknesses could be addressed through additional perspectives to better tailor it to local needs, thus assisting countries like Malawi in shaping their disability policies. Although Malawi has ratified the ADP, it still needs the ratification of one more country for it to come into effect (Alexiou, 2024). As a result, Malawi is unlikely to make any related policy changes until then. It will be interesting to see how Malawi incorporates both the ADP and CRPD and if they can effectively address the needs of its people.

While Malawi grapples with cultural factors affecting the domestication of the CRPD, the progress of other African countries domesticating the CRPD into national policies and implementing them also varies. In Nigeria, the CRPD has been domesticated into their local Discrimination against Persons with Disabilities (Prohibition) Act, 2018 (Anazonwu et al., 2022). However, not every state has domesticated and implemented it due to challenges in funding, lack of involvement of people with disabilities, and failure to recognize their needs (Anazonwu et al., 2022). On the other hand, policy makers and disability advocates in Zambia believe that the CRPD is successfully domesticated into their Persons with Disabilities Act of 2012 and the National Policy on Disability of 2015 (Cleaver et al., 2020). They view the domestication process as a linear ‘policy cascade’' wherein the international CRPD is translated into legislation, which is then further developed into policy (Cleaver et al., 2020). However, disability advocates, especially, are skeptical about the implementation due to the lack of knowledge of the policies among people with disabilities and the government (Cleaver et al., 2020).

Similar to Zambia and Nigeria's disability policy implementation challenges, Malawi experiences difficulties with capacity and the lack of policy knowledge in implementers, especially in the health sector. Malawi is believed to have good policies but lacks the capacity to have interventions to implement them. Given the small budget for disability issues in the country and the lack of disability specialists at the district level, it is unsurprising. The new Persons with Disabilities Act of 2024 outlines the Disability Trust Fund as a source to fund the implementation of disability programs (GoM, 2024). This may help resolve the funding issue, but there will need to be more monitoring to identify any changes.

As the Malawian government is burdened by financial challenges that prevent disability policy implementation, NGOs may also be able to play an effective supporting role in addressing this gap to meet the needs of people with disabilities. For Ghana, Malawi, Uganda, and other sub-Saharan countries, NGOs play a crucial role in the healthcare system by providing up to one-third of their clinical care (World Bank, 1993). Specifically, in Malawi, CHAM has provided 29% of health services to the country, including rural areas (Makwero, 2018). From this study, access issues in health, employment, and education for people with disabilities have been revealed to be lacking the most in rural areas compared to urban areas. NGOs have the potential to address these unmet needs in these hard-to-reach areas. However, there are several valid concerns about NGOs. One concern is their association with neoliberalism and the lack of inclusion for people with disabilities within these organizations (Wånggren et al., 2022). Another issue is the sustainability of the changes they bring and the potential overreliance on NGOs, which may lead governments to reduce their funding in areas where they do provide support (Lorgen, 1998). While NGOs are not perfect, and their relationship with governments requires careful oversight to ensure accountability, it is undeniable that they have made and will continue to make a significant impact in Malawi and other African countries.

Another factor that has hindered policy implementation in Malawi, especially in the health sector, is the lack of knowledge. Proper policy implementation also requires multiple stakeholders to be invested and knowledgeable about the policies (Shumba & Moodley, 2018). The lack of disability training has demonstrated how the majority of health workers could not name core national policies like the Persons with Disabilities Act, the Constitution of Malawi, and the National Disability Mainstreaming Strategy and Implementation Plan 2018-2023. During my time in Malawi, I participated in a training organized by the Ministry of Health for health workers (see Appendix D), specifically targeting those directly involved with patients, such as medical rehabilitation officers and ophthalmic clinical officers. The training included a group activity where participants defined disability and identified disability policies in Malawi.

Consistent with my findings, the majority of health workers predominantly applied the medical model and showed limited knowledge of policies. This emphasized the critical need for and value of such training sessions. During the session, health workers were taught a variety of information about understanding disability and the policies in the country, such as the new Persons with Disabilities Act of 2024, the National Rehabilitation Policy, the CRPD, Washington Group Questions, and the ICF model of disability. While this training was held for the first time by the government, I hope such initiatives continue, whether they are provided by the government or NGOs, and that they begin to reshape health workers’ understanding of disabilities and their knowledge of related policies.

Limitations and Future Directions

One limitation of this exploratory study was the small sample size of 29 individuals across Lilongwe and Ntcheu District. Given the short time frame, these two districts were selected due to convenience and known connections. As a result, it is not intended to represent the entire country of Malawi, and the findings cannot be generalized. Future studies should increase the sample size and include more districts in Malawi to generalize the findings and gain a more complete picture of how disability is understood in the country. In addition, there is an overrepresentation of voices from urban areas. With rural areas facing the most access difficulties, there needs to be more perspectives from this demographic.

The second limitation is that for health workers, there could have been more diversity in the departments that were sampled. The current sample includes health workers from the maternity ward, the under-five department, the tuberculosis unit, and general health workers who move around the health facility. Some health workers commented how the physiotherapy, orthopedics, dermatology, labor, and outpatient departments may have received more patients with disabilities and training. Interviewing these individuals may elicit important perspectives, especially if they interact more with patients with disabilities or have received more training on disabilities. Nonetheless, it is vital to ensure that all health workers have a basic understanding of disability and related policies, regardless of how frequently they interact with patients with disabilities, to prepare for when they do.

Another limitation was not intentionally including people with disabilities in the sample population. By coincidence, I was able to a small handful of participants with disabilities. Five participants had disabilities, three with albinism, and two with physical disabilities. Four were representatives of disability-related organizations, and one was a health worker. Their input was important and added valuable context to the landscape around disability in Malawi. However, future studies should prioritize speaking to people with disabilities, in larger quantities, with different types, in rural areas, and those in high positions within the government and health sector. This would greatly strengthen the findings of this study and add more nuance. As this project focuses on understanding disabilities and is about policies for people with disabilities, it is important for their voices to be represented. Future studies should expand the sample population to directly include people with disabilities, their family members, and community members. People with disabilities experience the direct impacts of how people around them understand disabilities and how policy is implemented. Family members of people with disabilities offer insights on how knowledgeable they are about disabilities, if and how they support their family member with a disability, and any challenges they face as a family. The status and support a family provides are crucial in shaping the respect a person with a disability receives, their self-esteem, health access and livelihood opportunities. For community members, they may interact with people with disabilities in their communities and have certain knowledge and beliefs about them.

This research was also very broad to capture the general understandings of disabilities. It would be interesting to focus more on certain disabilities like albinism and epilepsy or delve deeper into the intersections between disability, age, gender, and visibility. Certain disabilities were better regarded than others due to their visibility. However, the visibility of a disability can be a double-edged sword. People may be more understanding of a disability that they can see compared to one that they cannot. Consequently, people with less visible disabilities may not get their needs met or believe that they have a disability. Alternatively, visible disabilities may allow for more opportunities to be discriminated against in health, employment, and other settings.

Lastly, as a researcher, I am also aware that this study was conducted and conceptualized by people without disabilities. I see it as a limitation, and I hope that disability research in Malawi will be conducted by people with disabilities, especially Malawians. Although disability has affected my life, it cannot be compared to the lived experience of a person with a disability. Additionally, I had a Malawian interpreter assist me during interviews, but there were still opportunities for cultural and language barriers that could lead to misunderstandings. A Malawian with or without a disability could avoid these issues and communicate directly with participants in Chichewa.

Conclusion

This research explored how policy makers and policy implementers in Malawi defined and perceived disability on the ground. From interviewing government officials, disability-related organizations, and health workers, I examined how these perspectives and influences from the Global North affected disability policy domestication and implementation to improve health access and livelihood opportunities for people with disabilities in urban and rural areas. Delving deeper, I investigated if and how the CRPD and domesticated policies were able to adequately address the different cultural contexts of Malawi. This study emphasizes the complexities of disability understandings, various factors and challenges involved in policy domestication, and the progress of their implementation. It further demonstrates the need to engage with multiple perspectives to understand local situations on the ground and identify gaps between policy and practice.

The research has a few major findings. The first one is the participants’ understanding and perceptions of disability in Malawi. Generally, government officials and disability-related representatives had a deeper understanding that followed the social and the ICF model of disability. In comparison, health workers predominantly saw disability through the medical model. This dilution of understanding is due to a knowledge gap from the lack of disability training for health workers. Participants perceived that while disability understandings in the country have slightly shifted to be more aware and accepting, it is still very challenging and stigmatizing to have a disability. Respect for people with disabilities is connected to the type of disability, where physical disabilities are seen in a better light than other types that may be less visible and/or affect mental functioning. Additionally, employment can elevate how others perceive people with disabilities. With many people with disabilities begging in the streets and reinforcing the charity model, it contributes to the belief that they are lazy and incapable, resulting in disrespect. Having a disability in a rural area greatly differs from an urban area due to a lack of disability knowledge and limited access to education, health, and options for livelihood opportunities.

The second finding concerns the CRPD and how the country has domesticated it. Although there is progress through the development of national disability policies, there are challenges relating to Malawi’s financial and cultural landscapes. The CRPD favors countries in the Global North, leaving countries in the Global South to deal with the expenses needed to localize it to their country. Another factor is the cultural norms in Malawi that cannot be addressed through the CRPD. Rather than a domestication issue, the issue itself could be with the CRPD, which is why the African Disability Protocol may be used as a supplementary tool. Due to the shortcomings of the CRPD and the policies based on it, they are challenging to implement and, thus, unable to meet the needs of Malawians. Specific struggles with implementation are connected to lack of capacity, poor attitudes and lack of knowledge in implementers.

The final finding reveals that disability policies are not practiced in the health sector. Health workers have limited knowledge about the disability policies that they are supposed to implement. It appears that disability policies take more of a top-down approach in terms of development and implementation. From government officials to disability-related organization representatives and, lastly, to health workers, the policy information fails to trickle down to be implemented. Connected to a lack of knowledge, there are challenges in giving patients proper care due to health worker attitudes and lack of disability training. Health workers can engage in discriminatory behavior, such as refusing to provide medication and diminishing the needs of the patient. There needs to be active efforts to train health workers about disabilities and prevent these behaviors.

Overall, the area of disability is a work in progress in Malawi. Given the wide range of understandings and perceptions of disability among people with varying degrees of proximity to individuals with disabilities, changing attitudes requires the involvement of many stakeholders. Current efforts are a step in the right direction, but they are not enough. The rights and needs of people with disabilities should not only be addressed through effective policies on paper but also implemented on the ground to ensure they are being met.

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Appendix

Appendix A— Interview Questions

Government Officials and Disability-Related Organization Representatives (***Ogwira Ntchito M'boma ndi oimilira mabungwe omwe akugwira ntchito ndi anthu a ulumali)***

1. Can you introduce yourself and tell me about your role? ***Tandidziwitseni/Tandiuzani za mbiri yanu ndi kundiuza za udindo wanu?***
    a. How long have you worked in this position? ***Mwagwira ntchito kwa nthawi yayitali bwanji pa udindo umenewu?***
2. What is your role in health access policy development and implementation for people with disabilities? ***Kodi udindo wanu kapena gawo lomwe mumatenga nawo polemba ndi kuyendetsa ndondomeko zosamalira anthu a ulumali ndi otani/lotani?***
    a. ***What are the challenges? Ndi zovuta zanji zomwe zilipo pa nthcito imeneyi?***
3. What is disability? ***Kodi ulumali ndi chiyani?***
    a. What causes disability? ***Chimayambitsa ulumali ndi chiyani?***
    b. What types of disabilities are there? ***Ndi mitundu yanji ya ulumali yomwe ilipo?***
4. What does it mean to have a disability in Malawi? ***Kodi kukhala ndi ulumali kumatanthauza chiyani kuno ku Malawi***
    a. What can you say in terms of how people living with disabilities are respected? Probe for equality? ***Kodi munganenepo chiyani momwe anthu a ulumali amalemekezedwera? Maulumali onse amapatsidwa maulemu ofanana?***
5. How is having a disability different in an urban area compared to a rural area? ***Ndikosiyana bwanji kukhala ndi ulumali pamene uli mdera la mtawuni kufanizira ndi kukhala mdera la kumudzi?***
6. What are the societal expectations for an average Malawian – In terms of how one should live in their day-to-day life? ***Kodi anthu amayembekezera kuti m'malawi azichita zotani /azikhala bwanji pa moyo wake wa tsiku ndi tsiku?***
    a. How does having a disability affect these expectations? ***Kodi Kukhala ndi ulumali kumakhudza bwanji zoyembekezera zimenezi?***
    b. How does these expectations affect people living with disabilities in your view? ***Kodi zoyembekezera za anthu zimenezi zimawakhudza bwanji anthu omwe ali ndi ulumali?***
7. How does the government support people that are living with disabilities? ***Kodi boma limathandizapo bwanji anthu omwe ali ndi ulumali?***
8. Can people with disabilities work in the government? Probe for examples. ***Kodi anthu omwe ali ndi ulumali angagwire ntchito muboma? Perekani zitsanzo***
9. How do international entities like the United Nations influence disability policies in Malawi? ***Kodi mabungwe akunja monga United Nations amathandizila bwanji ndondomeko za ntchito yowona za ulumali kuno ku Malawi?* P**robe if they know other entities? ***Funsani ngati akudziwanso mabungwe ena?***

    a. *What challenges are there to adapt international disability standards in Malawi?* ***Ndi mavuto anji amene alipo pofuna kusintha ndondomeko kuti mutengere mulingo wakunja pa zaulumali muno mu Malawi?***
    b. My perception is that you are following UN models and conventions for disability, do you feel like they meet the needs of Malawians? ***Maganizo anga ndi oti mukutsatira chitsanzo kapena kutengera kwambiri ndondomeko ndi migwirizano ya United Nations popanga ndondomeko zaulumali kuno ku Malawi, kodi mukuona kuti ndondomeko zimenezi zimakwaniritsa zofunikira za a Malawi?***
    c. What are some areas for improvement? ***Ndi madera ati amene angakonzedwenso pa ntchito yokonza ndondomeko/malamulo okhudza anthu a ulumali mu dziko lino?***

10. Health access can be a concern for people with disabilities, how are government policies trying to address this? ***Kapezedwe ka chithandizo cha zaumoyo kakhoza kukhala kodandaulitsa kwa anthu a ulumali, kodi ndondomeko za boma zikuchitapo chiyani kuti zithane ndi zimenezi?***
    a. Are they effective? ***Kodi zikugwira ntchito mothandizadi?***
    b. Who implements disability policies related to health access? ***Ndi ndani amene amaika ndi kukwaniritsa ndondomeko za ulumali zogwirizana ndi kapezedwe ka zaumoyo?***

Health Workers ***(Ogwira ntchito za umoyo)***

1. Can you introduce yourself and tell me about your role? ***Tandidziwitseni/Tandiuzani za mbiri yanu ndi kundiuza za udindo wanu?***
    a. How long have you worked in this position? ***Mwagwira ntchito kwa nthawi yayitali bwanji pa udindo umenewu?***
2. What is disability? ***Kodi ulumali ndi chiyani?***
    a. What causes disability? ***Chimayambitsa ulumali ndi chiyani?***
    b. What types of disabilities are there? ***Ndi mitundu yanji ya ulumali yomwe ilipo?***
3. What does it mean to have a disability in Malawi? ***Kodi kukhala ndi ulumali kumatanthauza chiyani kuno ku Malawi?***
4. What can you say in terms of how people living with disabilities are respected? Probe for equality? ***Kodi munganenepo chiyani momwe anthu a ulumali amalemekezedwera? Maulumali onse amapatsidwa ulemu mofanana?***
5. How is having a disability different in an urban area compared to a rural area? ***Ndikosiyana bwanji kukhala ndi ulumali pamene uli mdera la mtawuni kufanizira ndi kukhala mdera la kumudzi?***

6. What are the societal expectations for an average Malawian – In terms of how one should live in their day-to-day life? ***Kodi anthu amayembekezera kuti m'malawi azichita zotani /azikhala bwanji pa moyo wake wa tsiku ndi tsiku?***
    a. How does having a disability affect these expectations? ***Kodi Kukhala ndi ulumali kumakhudza bwanji zoyembekezera zimenezi?***
    b. How does these expectations affect people living with disabilities in your view? ***Kodi zoyembekezera za anthu zimenezi zimawakhudza bwanji anthu omwe ali ndi ulumali?***
7. How often do you interact with patients with disabilities? ***Kodi Mumakomana pafupipafupi bwanji ndi odwala omwe ali ndi ulumali?***
8. Do patients with disabilities receive the same care as patients without disabilities? ***Kodi odwala omwe ali ndi ulumali amalandira chisamaliro chofanana ndi odwala omwe alibe ulumali?***
    a. How so? ***Zimakhala bwanji?***
9. Some patients with disabilities might have a hard time receiving health care, what do you think is the reason? ***Odwala enatu amene ali ndi ulumali amatha kuvutika kuti alandire chisamaliro chazaumoyo, kodi mukuganiza kuti chifukwa chake ndi chiyani?***
10. As a rural/urban health care worker, how different would it be to work in a rural/urban area? ***Monga inu ogwira ntchito yazaumoyo kaya akumadera akumudzi kapena mtawuni, pali kusiyana kotani kugwira ntchito kumadera akumudzi kapena mtawuni?***
    a. How would your interactions with patients with disabilities be different? ***Kodi makumanidwe anu ndi odwala omwe ndi aulumali angakhale osiyana bwanji ngati muli ku tawuni kapena kumudzi?***
11. How do you implement government policies? ***Mumaika ndi kukwaniritsa bwanji ndondomeko za boma?***
    a. What are some challenges? ***Ndimavuto ena anji omwe mukukumana nawo?***
    b. Have you ever received training on disability? Probe, When, offered by who, content if possible. ***Kodi munalandilapo maphunziro a za ulumali? Liti, anapereka ndani, munaphunzirapo zotani***
    c. How often do you receive refresher training about disability? Probe, by who? ***Mumalandira pafupipafupi bwanji maphunziro obwereza okhudzana ndi za ulumali?***

Appendix B—Chichewa Consent Form for Interviews

Moni, Dzina langa ndi Johanna ndipo ndine mwana wa sukulu ku School for International Training Graduate Institute ku Vermont ku America. Mkafukufukuyu ndikufufuza m'mene amalawi amamvetserera za ulumali ndi m'mene ulumali umalumikizidwira pa nkhani zaumoyo ndi kapezedwe kamunthu pakhomo. Cholinga cha kafukufukuyi ndi kufuna kumvetsetsa bwino za m'mene ulumali umaonedwera m'madera akumudzi kapenanso ku tawuni mu malawi ndipo m'mene anthu a ulumali amakhalira mu magulu a anthu. Izi zikulunjika ku cholinga chofuna kufotokozera m'mene kumva kosiyanasiyana pa za ulumali ndi chikhalidwe zingathandizire ndondomeko zakapezedwe ka zaumoyo ndi chitukuko ndi kakhazikitsidwe kantchitoyi kuti zithandizire bwino anthu omwe ali ndi ulumali.

Mafunso awa akhoza kukhala okamba za inu eni komanso ovuta kuwakamba, koma ngati mwatopa kapena simukufuna kuyankha, muli ndi ufulu wosayankha panthawi ina iliyonse. Ndikadakonda kuti ndikufunseni mafunso ena okhudzana ndi maganizo anu pa za ulumali, zomwe mwadutsamo pakulumikizana ndi anthu omwe ali ndi ulumali, kapena kukhala ndi ulumali kumene. Mwayenera kukhala a zaka 18 kapena kuposera apo kuti mutengepo mbali.

Macheza awa atha kutenga ola limodzi la nthawi yanu. Mukhoza osayankha funso lina lililonse ngati mwakonda kutero. Mukhoza kuimitsa machezawa panthawi iliyonse popanda kulandira chilango chamtundu uliwonse kapena kutaya phindu lililonse. Ndemanga zanu zizakhala zachinsinsi. Muli ndi ufulu wosatengapo mbali panthawi iliyonse. Tidzagwiritsa ntchito zomwe mutiuze pantchito ya kafukufukuyu komanso kuzifalitsa polemba. Ngati muli ndi mafunso kapena madandaulo aliwonse, mukhoza kuimbira foni pa nambala ali pansiwa. Muli ndi funso lililonse? Mungandipatse chilorezo kuti ndipitirize? Ndikotheka kuti ndizilemba za macheza athuwa? Ndikotheka kuti nditepe mau anu mumacheza athuwa kuti ndionetsetse kuti ndamasulira bwino lomwe mayankho anuwa?

Ngati Mwavomereza kutenga nawo mbali mu kafukufukuyu, chonde lembani dzina lanu:
____

Saini: __________________________________

Tsiku: ___________________

Local Research Team	Local Ethics Committee	My supervisor

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Appendix C—English Consent Form for Interviews

Hello, my name is Johanna, and I am a student with the School for International Training Graduate Institute in Vermont, USA. In this research, I will be examining how Malawian policy developers and implementers understand disability and how this interacts with health access policies and livelihood opportunities. The objective of this research is to better understand how disability is perceived in a local Malawian context and in different geographical regions (urban, peri-urban, and rural). This aims to explain how different understandings of disability and cultural factors can influence government health access policy development and implementation to better support people with disabilities.

These questions might be personal and uncomfortable, but if you are tired or do not want to answer, you have a right to not answer at any point. I would like to ask you some questions about your perception of disability, experience on interacting with people with disabilities, and your role in policy making or policy implementation for people with disabilities. You must be 18 years of age or older to participate.

The interview may take up to one hour of your time. You do not have to answer any questions if you do not wish to answer. You may stop the interview at any time without penalty or loss to benefits. Your comments will be confidential. You have a right to not participate in the study at any time. We will use this information for research and publication. If you have any questions or concerns, you can call the numbers below. Do you have any questions? Do I have your permission to proceed? Is it OK if I take written notes of our conversation? Is it OK if I audio record our conversation to make sure I have interpreted your answers correctly?

If you agree to the study, please print your name: ______________________________________

Signature: __________________________________

Date: ___________________

Local Research Team	Local Ethics Committee	My supervisor

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Appendix D— Attended and Presented at a Disability Training for Health Workers