#### Report on

The Convention on the Rights of Persons with Disabilities: Law, Civil Society, and Youth Partners from the Least Developed Countries

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## EXECUTIVE SUMMARY

This report aims to provide insight into key concepts in the Convention of the Rights of Persons with Disabilities (CRPD), particularly as they relate to the world's least developed countries (LDCs), the barriers those countries face in implementing the principles of the convention, and the key role of civil society organizations in addressing those challenges.

Section I discusses the conceptual underpinnings of the CRPD, including central debates over the definitions of disability (whether approached through a medical or social model) and reasonable accommodation. Whereas theorists within disability studies generally support a social model of disability, which emphasizes the need for societal change to accommodate all persons, rather than understanding disability as an impairment in the individual, the CRPD tries to bridge the gap between models. The coexistence of different approaches leads to varying interpretation of social equality (whether it should be formal or substantive) and of what constitutes the right to and responsibility for reasonable accommodation - the centerpiece of the CRPD. LDCs typically adopt more of a medical approach to disability, perhaps in part because they lack the resources to implement the kind of structural changes the social model demands, although there are some exceptions among the country reports in how they approach disability. This section concludes with an examination of an ethics of care approach to disability, arguing that it emphasizes reciprocity in care relationships (and thus positions disabled persons as agents in those relationships), but also runs the risk of replicating the privatization and feminization of disability care.

Section II considers the structural and contextual conditions within the LDCs that impact CRPD readiness and present barriers to implementation. These barriers include the lack of a normative human rights culture and persistent stigmatizing beliefs surrounding disability and weak infrastructures, often related to poverty and war, that result in low literacy rates and limited

healthcare, all of which disproportionately affect and often correlate to disabled populations. The section also emphasizes the intersectionality among these factors and the need for multi-faceted and locally-based approaches to equality and reasonable accommodations. Especially in the context of weak states, civil society organizations have an important role in promoting the rights of persons with disabilities. Section III draws on the LDC country reports and additional research to identify commonalities among civil society disability organizations and potential models. The research indicates two dominant identity-based approaches: organizations focused on women and children and those focused on visual and aural impairment. The section also notes organizations devoted to particular professions and to sports as offering creative models for promoting disability rights and services.

The report concludes in Section IV with an overview of civil society organizations from the LDCs focused specifically on youth with disabilities and on the foundational disability rights principle that persons with disabilities must have central roles in determining the shape and scope of their own rights.



## RESEARCH METHDOLOGY AND TERMINOLOGY

Research for this project took place in the spring of 2023 and included legal analysis, theoretical readings in disabilities studies, analysis and coding of country reports from the least developed countries of the United Nations to the Convention on the Rights of Persons with Disabilities and related conventions, and web-based and secondary source research on civil society organizations related to disability rights and services in the LDCs.

Discussions surrounding the CRPD and within disability studies more broadly include debate over the use of the terms "persons with disabilities" versus "disabled persons." Although we sometimes vary the phrasing, we follow the lead of scholars who advocate for "persons with disabilities" to avoid implying that disability necessarily constitutes an individual's entire identity. In the section on cultural practices, healthcare, and disabilities, we follow the United Nations in using the term female genital mutilation (FGM).

The research resulted in two reports: the one below and the companion "Report on Civil Society Organizations for the Rights and Services of Persons with Disabilities: An Overview of Partners from the UN's Least-Developed Countries" which lists each country along with major civil society disability rights and services partners, a general synopsis of each organization, and any contract information for the organization that was available.

#### SECTION I: AN OVERVIEW OF THE LEGAL AND CONCEPTUAL TENETS OF THE CRPD

#### Introduction

This section discusses the legal and theoretical debates that informed the drafting of the CRPD, with special attention to their application to legal doctrines and reports from least developed countries (LDCs). We place the CRPD in conversations with varying definitions of disability and understandings of reciprocal care-giver/care-recipient relationships to better understand how nations have responded to the standards set forth by the declaration.

The CRPD begins in its Preamble and Article 1 with an expansive, yet somewhat indeterminate definition of disability. The Preamble notes that "[d]isability is an evolving concept, and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder full and effective participation in society on an equal basis with others." This definition implicitly recognizes debates over medical versus social models of disability and raises the question of" how full and effective participation...on an equal basis" should be defined and guaranteed. The CRPD challenges traditional notions of how human rights are realized. The CRPD emphasizes positive rights for those with disabilities because of its focus on the societal dimension of disability.

Central to the CRPD is the concept of accommodation, which challenges traditional human rights notions of universality and formal equality that aims to treat everyone the same, instead endorsing substantive equality that requires individualized accommodation for those with disabilities. Perhaps problematically, the concept of reasonable accommodation implies a malleable threshold of undue burden on the part of the accommodation provider, which complicates enforcement due to the fact that the duty to accommodate individuals with disabilities is often dispersed among non-state individuals.

As noted above, another barrier to understanding and achieving the standards set forth by the CRPD arises through the use of competing theories of 'disability' through the medical and social models. In our research into the CRPD reporting of Least Developed Countries, we found that countries primarily adopt the medical model through solution-based efforts, while other nations have relied on the social model through public-facing activism. The incorporation of these varying definitions of disability in government reporting and policy makes it difficult for human rights organizations, like the United Nations, to analyze national efforts to protect disability rights and work towards the implementation of a more unified approach. A framework for the ethics of care model can be found In Nirmala Erevelles' Disability and Differences in Global Contexts (2011) as she argues for a productive caring relationship that adheres to reciprocity, mutual recognition, and respect as opposed to a donor-recipient model of support. However, she notes, as all care relationships are framed in relation to autonomy — a level of independence that is posed as the intention of care, disabled communities are often still disadvantaged in these systems. When it comes to the United Nations, an organization whose focus covers an international betterment through aid and protection, an ethics of care could only emerge through the capacity-building of local organizations who could directly facilitate reciprocal models of support.

#### Legal Frameworks

The CRPD differs from other human rights instruments because of its emphasis on positive rights and its focus on the societal factors that shape our concept of disability. The CRPD emphasizes the environmental barriers that handicap people with disabilities, putting the burden on the state and society to restructure themselves to integrate people with disabilities (Megret 507).

Fundamental human rights like the right to participation require calls to action in the CRPD, as "lack of participation in society and in the community is seen both as an inherent part of the very definition of disability" (Megret 508).

Stating that people with disabilities have the right to participate in society is not enough; accommodations must enable people with disabilities to participate. The CRPD emphasizes the autonomy of people with disabilities, who are often infantilized by nature of not being able to access or participate in many aspects of society. The document enumerates the rights of people with disabilities to choose where they live, who they marry, and how to raise their children (CRPD 13–15).

The CRPD challenges traditional notions of how human rights should be realized. Megret and Mispa argue that human rights are grounded in the ideas of universality and formal equality which involve treating everyone similarly (Megret 496; Megret & Msipa 262). Because disability is such a broad and debated category consisting of many different groups and because providing accommodation for people with disabilities involves supporting their unique needs, this framework is flipped on its head by the CRPD's concept of accommodation. This is illustrated in Article 29 of the

Democratic Republic of the Congo's constitution, which states people with disabilities are entitled to "specific measures of protection in accordance with their physical, intellectual, and psychological needs" (Democratic Republic of the Congo CESCR Country Report 2013, 10). The CRPD includes a duty to provide reasonable accommodation (Megret & Msipa 258), but it is difficult to impart this international standard into domestic practice (Megret & Msipa 260). This is perhaps illustrated by abstract promises from governments like that of Bangladesh, which reported in 2018 that they were "planning for provisions" for "personspecific reasonable accommodation in the short term" (Bangladesh CRPD Country Report 2018, 11).

The concept of accommodation itself has been resisted, with many states not incorporating explicit provisions on reasonable accommodation (Megret & Msipa 260), partly due to a lack of clarity on what accommodation looks like in practice (Megret & Msipa 261). One of the greatest hurdles to the global adoption of the concept of reasonable accommodation might be the characteristic of human rights that equates treating everyone equally with treating everyone the same

(Megret & Msipa 264). The CRPD's emphasis on accommodation, although vague, allows an important shift from formal to substantive equality, grounded in the belief that people should be able to participate in society equally in spite of their differences, taking into account people's unique characteristics and barriers to participation (Megret & Msipa 264). Fortunately, these ideas are beginning to permeate some countries' legal frameworks, such as in Ethiopia, where "reasonable accommodation, undue burden, and universal design" are newly introduced to legal jurisdiction (Ethiopia CRPD Country Report 2015, 5). In practice, it can look like Uganda's effort to ensure reasonable accommodation through the modification of new public building designs to ensure easy access for persons with disabilities (Uganda CRPD Country Report 2013, 47). However, we still see states grappling with the complex implications of these terms. For instance Myanmar's 2017 report on the CRPD identifies a need to educate stakeholders, the general public, and the private sector about what "reasonable accommodation" means (Myanmar CRPD Country Report 2017, 5). In addition to considering what accommodation requires, the meaning of the term reasonable is also controversial, with different meanings nationally, regionally, and internationally (Megret & Msipa 265). Reasonable accommodation implies a subjective weighing of undue burden versus the effectiveness or importance of the accommodation, which can result in disagreement (Megret & Msipa 269). Additionally, the duty to accommodate individuals with disabilities is often dispersed among non-state actors, which makes enforcement and standardization more complex.

People with disabilities are more susceptible to rights violations by individual private actors than the state, so non-state actors play the unique role of having to facilitate reasonable accommodation (Megret & Msipa 270).

#### Social v Medical Model

The central struggle to understand global efforts to protect the rights of individuals with disabilities and to determine "reasonable accommodation" stems from competing theoretical approaches to disability articulated through the medical and social models. Not only do definitions of disability vary between countries, but oftentimes countries incorporate components of both models, perpetuating ambiguous and contradictory methods of understanding disability in an effort to accommodate diverse perspectives on what constitutes a disability.

The medical model has historically been employed to define disability as an "affliction' caused by the particular condition or impairment" that can be remedied by some sort of cure or treatment so that the individual "may be assimilated to the social norm" (Kayess & French 2008). This model has been incorporated into national approaches to disability issues as a means to grapple scientifically with the issues that arise for people with disabilities by tackling what the model understands as the source of the issue: the impairment. For instance, under the authority of the previous two regimes, Ethiopia has enforced mandatory institutionalization for those who demonstrate symptoms of mental impairments (Ethiopia CRPD Country Report 2015). This interaction with disability forces individuals who do not fit able-bodied norms into facilities separated from society with no means to achieve equitable resources and experiences. Rather than making society a more inclusive space for able and disabled bodies, the Ethiopian government stigmatizes disability in a way that separates the individual from society, rather than address the barriers that disabled people face in society.

Like Ethiopia, Gambia has responded through medical and remedybased methods to disability as its Department of Social Welfare supplies "5,000 disabled persons with artificial limbs and walking sticks and/or frames" (Gambia CESCR Country Report 2019). Through this policy, the Department of Social Welfare has promoted the adaptation of disabled bodies to ablebodiedness standards by providing equipment to "restore" the body to the norm. Ultimately, the implementation of policies and practices based in the medical model prioritize altering the disability so that people may participate in pre-existing spaces. To the extreme, the medical discriminatory public and institutional practices that directly disservice those with disabilities; however, it may also lead to adaptive technologies to ease mobility and other forms of social participation.

In contrast to more "solution" based approaches to disability, the social model redefines society as the entity that makes impairment disabling. Thomas Shakespeare, whose research centers on the societal consequences of impairment, describes the social model as a method of understanding disability as "something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society" (Shakespeare 2013). This conception challenges the idea that individuals with a disability are somehow "lacking" and forces us to recognize how society upholds able-bodiedness as a standard not easily attained by everyone.

Our research indicates that LDCs have primarily interacted with the social model through community engagement efforts. Although none of the countries we researched have explicitly incorporated language from the social model, several countries have successfully implemented policies rooted in this approach, particularly through community-facing projects that have aimed to educate the public. Bangladesh, for example, has enabled a social model approach through its awareness campaigns for disability rights, specifically through its efforts to make television more accessible for those who are hearing impaired (Bangladesh CRPD Country Report 2019). Ethiopia has taken a similar approach by disseminating information on disability rights issues through weekly programs (Ethiopia CRPD Country Report 2015). Efforts of countries like these to increase accessibility and tackle stigmas encourage the idea that the structure of the society is lacking rather than the individual with an impairment. The integration of this model into government policies and CRPD reports has made society more accessible through its ability to reframe disability as an inclusive identity. This model has effectively created the opportunity for the "liberation of disabled people" through more targeted efforts to remove societally-imposed obstacles, and the establishment of a

collective identity founded in inclusivity and shared experience (Shakespeare 2013).

Although the social model promises a more intersectional understanding of disability, the approach does not adequately address the unique experiences of those with disabilities. Regardless of the advantages of recognizing society as an exclusive force through its interaction with disability, the application of the social model fails to engage factors such as the individual's health, wellbeing, and individual capacity (Kayess & French 2008). The distinction between impairment and disability can perpetuate an unrealistic utopia that suggests that in the perfect world, an individual with disability might not face any obstacles, physical or mental, that may impact their ability to participate to the same extent as an able-bodied individual (Shakespeare 2013).

Even with its obvious shortcomings, academics seem to prefer the social model, arguing that the approach is "indispensable" though imperfect, while the medical model perpetuates an understanding of disability as a stigmatizing lack (Shakespeare 2013). However, the struggles of both the medical and social models to comprehensively define disability continues to unfold on a global stage through discrepancies between which approach individual governments and the United Nations choose to incorporate into their legal frameworks and rights declarations. Although strictly defining disability raises concerns about attempting to make static a constantly changing identity, varying understandings of disabilities and approaches to inclusiveness make analyzing a government's efforts to actualize disability rights and implement a universal approach nearly impossible.

### Ethics of Care

Traditional ethical theory develops a basis for what the world should be like from a smaller individual level to a larger wide-scale context. It accounts for the "autonomous, rational, moral agent, who independently judges the conflicting claims of others against an abstract and universal standard of equality or equal respect" (Erevelles 2011). How we understand disability and disability studies is complex because their definitions are linked to how autonomy is understood and how it relates to ethics of care. It raises the question: how can disability studies be understood within the framework of ethical theory if autonomy is unclear and misconstrued?

Erevelles offers an approach in Disability and Difference in Global Contexts that puts disability studies in a global context. Disability is described here as "the embodied experience of social oppression constituted via the inhospitable social, cultural, and economic structures in mainstream society" (Erevelles 2011). That is, disability spills past just the physical, and is also concerned with its construction and perception reinforced by institutions and structures. Erevelles advises that a productive system for the ethics of care is one that is rooted in reciprocal relationships where there is both respect and mutual recognition. The ethics of care model is generally considered a feminist approach as it problematizes the male-centered moral theory and highlights how these traditional theories disregard values / morals typically related to women or considered 'feminine' culturally across society whereas a feminine ethics of care model calls for the inclusion of women in its model. Erevelles frames her approach to ethics with feminist theory, noting that a "feminine ethics of care" can also be exploitative because it calls for women to perform at the expense of themselves. In understanding the detrimental potential of care relationships, discussions of the complexity of autonomy in relation to the disabled body are essential. Discussions of ethics of care models must address who provides care, the scope and substance of reciprocity in care relationships, and the extent to which the state casts its responsibilities to persons with disabilities to the private sphere.

#### SECTION II: STRUCTRUAL AND CONTEXTUAL CONDITIONS THAT IMPACT CRPD READINESS

This section provides an overview of the structural conditions and foundational issues that limit LDCs' CRPD readiness. These conditions include: a lack of human rights culture, material conditions including low levels of education, lack of basic healthcare, war, pervasive poverty, and lack of infrastructure. According to LDC reports, stigmas surrounding various disabilities persist and lead to social ostracization, especially in the absence of a normative human rights culture. High levels of illiteracy and limited educational resources and healthcare also disproportionately affect disabled and other vulnerable populations. LDCs also report the long effects of violent conflicts that produce disabilities, destroy infrastructure, and limit national resources, including basic healthcare and access to services, available for vulnerable groups. The reports indicate that the conditions addressed below are intersectional and must be addressed through comprehensive, yet locally-grounded interventions.

#### Lack of Human Rights Culture

Many of the LDC reports to the CRPD and related conventions identify the lack of a shared culture of human rights as a barrier to the recognition and protection of disability rights. Especially in countries where local cultural practices and beliefs stigmatize disabilities, the principles of the CRPD often fail to take root. While it is important to respect unique lived experiences and histories which are deeply tied to many cultural practices and beliefs, it is just as important to identify practices which directly violate fundamental human rights. The extent and legality of FGM varies by locale; and it sometimes occurs openly even when legal prohibitions exist. According to an article published by the UN Population Fund, "FGM is carried out as a way to control women's sexuality... It is thought to ensure virginity before marriage and fidelity afterward," and in many places can be considered a prerequisite for marriage ("FGM Frequently Asked Questions," UN Population Fund). In addition to its role in controlling women's sexuality, FGM is a clear violation of the human right to health, as it can cause severe pain, bleeding, infection, and even death. It can also lead to long-term health problems such as urinary and reproductive tract infections, infertility, and complications during childbirth. The procedure is often performed without anesthesia, using unsterilized instruments such as knives, scissors, or razor blades, and it can cause intense pain and suffering. Moreover, the practice is usually imposed on girls without their consent, and they are often subjected to social pressure and stigmatization if they refuse ("FGM Frequently Asked Questions" UN Population Fund). It is abundantly clear that this practice violates the fundamental human rights of women, including by causing them to be considered disabled under the medical model and formal definitions used by the UN by leaving women with "long-term physical... impairments." In places where persons with disabilities already face discrimination, it becomes an even more urgent issue.

FGM is common in a variety of LDcs with a cross-section of different ethnic groups and religions, and responses must be tailored to local contexts. For example, in the United Republic of Tanzania, the government is aware of high rates of FGM and reported it, but said they lack funding to provide statistics or specific areas where it is happening. This means that more formal study is needed before a response can be implemented (Rep. United Republic of Tanzania CEDAW 2014). FGM also intersects with socio-economic factors in some countries where it is more prevalent amongst the poor or other marginalized groups. Here, disability, gender discrimination, and poverty intersect and could only be addressed through a holistic approach to disability's structural roots (e.g., Rep. Gambia to CEDAW).

Other countries reported the ongoing stigmatization of people with disabilities, including the belief that their disabilities indicate malevolent supernatural powers that threaten the community. Stigmatizing beliefs can lead to persecution, hiding people with disabilities, and death. In one particularly striking example of an attempt to address such stigmatizing beliefs, the Democratic Republic of Congo (DRC) reportedly addressed widely held beliefs in witchcraft associated with disabilities by presenting anti-discrimination laws as protections for non-disabled population from the supernatural forces (rather than protecting persons with disabilities) (DRC Eighth Periodic Report, 2017). Similarly, in Togo, cultural factors such as the belief that disability is a curse or punishment from God, can hinder the implementation of the CRPD when aid, services, and accessibility are criticized as sacrilegious (Togo CRPD Country Report 2019). It is difficult to discern from the country reports alone whether discrimination based on cultural beliefs is adequately reported.

The reports indicate the difficulty in countering commonly held beliefs about persons with disabilities and the danger cultural relativism poses to human rights protections. Other countries, such as Togo, note the gap between legal protections and protections in practice of disability rights (Togo CRPD Country Report 2019). Because of the obstacles that culture can pose, any solutions must be developed locally with local stakeholders, including disabled persons, their allies, and human rights groups.

#### **Structural Conditions**

By definition, LDCs often suffer from high rates of poverty, illiteracy, and unemployment and limited access to resources, and those factors create obstacles to the adoption and implementation of the CRPD.

Non-compulsory education and the lack of schools create high illiteracy rates nation-wide and limit educational opportunities for disabled persons as well as the ways in which their rights can become normative. For instance, children in LDCs attend 2.8 fewer years of school compared to the world average (UNCTAD 2021). In Benin nearly 70% of the population is illiterate (Benin CPRD Country Report 2018). There are also high rates of illiteracy in addition to extreme poverty and a lack of educational services in Rwanda, Zambia, and Sierra Leone (Rwanda CRPD Country Report 2019; Sierra Leone CRPD Country Report 2018; Zambia CRPD Country Report 2017). These trends also disproportionately affect women and girls. Gender gaps in LDCs are still prominent with gender gaps in education seen in more than 70% of

the countries. (UNCTAD, 2021).

Within the LDCs, persons with disabilities face additional barriers to education. In 2008 and 2009 only 47% of the disabled population of Myanmar attended schools (Myanmar CRPD Country Report 2017). In Kiribati in 2015, only 16% of persons with disabilities had access to education. Additionally, females with disabilities in Kiribati have the lowest literacy rates in the country (Kiribati CRPD Country Report 2015). This is also seen in Ethiopia where although "the inequality of women with disabilities is understood and obvious, no legislation has been made in official recognition of this inequality" (Ethiopia CRPD Country Report 2015, 12).

The LDCs report some successes in advancing education for persons with disabilities. In Bangladesh, the government set up five schools for youth with disabilities and continues to develop integrated programs for students with disabilities at existing schools (Bangladesh CRPD Country Report 2018). However, there needs to be more action taken to close the gaps in education throughout all of the LDCs to further advance the rights of disabled persons.

In addition to education, LDCs' low standard of living can be observed in the poor infrastructure, unstable economies, high unemployment, and a lack of human resources in the country. However, for the purpose of this report, healthcare will be the main assessment of the low standard of living. LDCs suffer from a lack of basic healthcare and have a low life expectancy, conditions which create obstacles to CRPD readiness. Haiti, the poorest country in Latin America, is taking steps to "promote a policy of mutual medical aid for disadvantaged persons with disabilities, in the form of a contributions-based insurance scheme" because insufficient healthcare disproportionately neglects the disabled community (Haiti CRPD Country Report 2018, P. 23). Mauritania ranked disease as their first cause of disability, thus also emphasizing the correlation between healthcare and disability (Mauritania CRPD Country Report 2017). The lack of basic healthcare impacts disability rates in terms of both causes and treatments/services. This creates a cycle of healthcare neglect toward disabled individuals. In Benin, where fifty percent of the population is under eighteen years of age, "persons

with disabilities are being treated as a priority"; however, as healthcare resources are limited most disabled people still lack basic care (Benin CRPD Country Report 2018, 22).

Some LDC reports attributed the lack of healthcare and poor standard of living to war or the history of war. War also directly leads to disability. In 2017, Angola reported 656,258 individuals with disabilities, many a result of armed conflict (Angola CRPD Report 2017). Similarly, Sierra Leone was engaged in civil war for eleven years which led to widespread disabilities including hearing impairments as a result of the heavy machinery and automatic weapons (Sierra Leone CRPD Report 2018). Rwanda has high levels of disabilities, some of which are a result of cultural and ethnic violence. Rwanda's report includes a concern regarding "[p]revailing violence, abuse and neglect against persons with disabilities, particularly women and children and persons with intellectual or psychosocial disabilities, within health-care and corrective institutions" (Rwanda CRPD Report 2019, 6). There is also evidence of an indirect relationship between war and CRPD's readiness because political authority is unstable and war perpetuates a lack of resources and an increase in CPRD challenges.

Country reports also cited poverty as a foundational cause of disability or barrier to CRPD implementation. For example, Kiribati reports poverty is often connected to disabled individuals and harms a nation's ability to meet the needs of disabled people (Kiribati CRPD Report 2015). The conditions of poverty and lack of resources are displayed in the lack of access to facilities, unavailability of technology, and absence of data. For instance, eighty percent of disabled individuals live remotely without access to resources in the Solomon Islands (Solomon Islands CRC Report, 2002). Zambia reports a lack of technology to adequately report (Article 31 of the CRPD) and respond to disabled populations (Zambia CRPD Report 2017). Research is arguably the first step to CPRD readiness, and if a country can not accurately assess its disabled population then enforcement of the CPRD is jeopardized.

#### SECTION III: LCD CIVIL SOCIETY PARTNERS TO PROMOTE THE RIGHTS OF PERSONS WITH DISABILITIES

Civil society partners are an important component of securing rights for persons with disabilities in the LDCs. The robustness of these domestic civil society organizations correlates to the robustness of society as a whole, according to their country reports to the CRPD. Civil society organizations related to disability rights have several notable commonalities, including a focus on the rights of women and children with disabilities, as well as blind and deaf individuals. There were also a handful of interesting outliers such as The Angolan Association of Traders and Street Vendors with Disabilities that might provide models for other countries. In addition, we evaluated specific civil society partners that have had significant impact on the rights of persons with disabilities within their countries.

#### **Importance of Civil Society Partners**

Civil society partners play a vital role in society. These are organizations independent of the government and the for-profit sector that seek to further community interests. In fragile and conflict ridden countries they often provide services that should ordinarily be the responsibility of the state and business. Civil society partners also play an important role in holding governments accountable for their actions. They often do this through monitoring government policies as well as holding them responsible for reporting institutions like the UN. Civil societies are a source of information and services while also heavily engaging in advocacy. They defend citizens' rights and work on the ground within communities to enact change. Real progress depends upon organizations working within communities with the people who are most in need of assistance.

Across the LDC reports to the CRDP many countries mention numerous civil society organizations while others mention none. Those countries with numerous active civil society partners seem likely to have success implementing programs and pushing through initiatives. There are many international civil society organizations; however, we are particularly interested in domestic organizations within the LDCs. These organizations are doing local work with a local mission specific to the needs of their community.

#### **Civil Society Areas of Focus:**

In reviewing the civil society partners in the LDCs, we noticed numerous organizations related to deafness, blindness or other visual impairments, as well as organizations focused on women and children. In many countries there are civil society organizations related specifically to visual impairment. Examples include the Gambia Organization of Visually Impaired, the National Centre for the Rehabilitation of Blind Persons in Sudan, Sightsavers Senegal, the National Association for the Near-Sighted and the Blind Angola, the Afghanistan International Foundation for the Blind, and the Rwandan Union of the Blind. All of these groups seek to advance the rights and standard of living of blind people within their country. It is interesting to see so many civil society organizations specifically focused on the rights of the blind. This could be due to the large number of individuals with visual impairments as well as the visibility of the disability. Aside from blindness, deafness was the only other specific disability that had many dedicated civil society partners.

Gambia, Uganda, Sierra Leone, Eritrea, Ethiopia, Mauritania, Lesotho, United Republic of Tanzania, and Kiribati all have local civil societies partners advocating and providing services on their behalf. The Ethiopian National Association of the Deaf has 28 branches throughout Ethiopia and provides sign language training in the most remote parts of Ethiopia. The Gambia Association of the deaf and Hard of Hearing aims to increase socio-economic capacity, train, develop, and counsel deaf people and their families. Kiribati Deaf Association works to promote deaf inclusivity and teaches sign language classes to hearing people. Other civil society partners focused on specific populations, especially women, as opposed to specific forms of disability. There are some organizations that specifically mention women such as the National Union of Women with Disabilities of Uganda, Organization of Women with Disabilities in Sudan, and Nepal Disabled Women Association, and there are other organizations such as Afghanistan International Foundation for the Blind, Accessibility Organization for Afghan Disabled, Congo Handicap, La Fondation Internationale Tierno Et Mariam (Guinea), Disabled Persons International (Mauritania), Myanmar Federation of Persons with Disabilities, and Humanity and inclusion in Senegal who put an increased emphasis on women and children. Women and children with disabilities face disproportionate rates of violence and maltreatment which is why it is important that civil societies like the ones listed above exist.

Another theme that we recognized when evaluating the civil society partners in our data set was the attention to children with disabilities. One example of an organization geared towards aiding children with disabilities is the Komar Pkar Foundation in Cambodia. This organization directly translates to the Foundation for Disabled Children. The goal of the foundation is to aid children and young people – and their families – with moderate and severe disabilities. In addition, another child and youth related organization is the Kiribati School and Centre for Children with Disabilities in Kiribati. This organization was established in 1991 and is the only school in Kiribati that educates and aids children with disabilities. This school educates children with various physical and mental disabilities. Both sign language and braille are taught for children with hearing and vision impairments. Currently they are educating over 200 children.

Another example of an organization that focuses on youth is the Freetown Cheshire Home in Sierra Leone. The mission of this local group is to provide accommodation and education to young children. A major issue in Sierra Leone is the lack of access to clean and safe water, and the children at Freetown Cheshire Home have suffered as a result of this major problem for years. Many of the residents have physical disabilities and are unable to carry water or operate the water pump on their own because it was damaged. One more example of a child-related organization is the Uganda Society for Disabled Children. The Uganda Society for Disabled Children supports children with disabilities and their parents access the resources and opportunities they need to achieve their full potential and lead fulfilling lives. This organization provides medical and educational support to individual children, working closely with their families and their communities, as well as partnering with government staff in the health, community and education sectors.

#### **Organizations of Note**

In addition to organizations devoted to the groups noted above, there were a few organizations with more distinctive concerns and constituencies. One example was The Angolan Association of Traders and Street Vendors with Disabilities (Angola CRPD Report Section 2.4). This organization in Angola is responsible for encouraging people with disabilities to engage in trade in order to gain financial stability. The target group of this organization falls onto a smaller portion of the Angolan population, making it a unique outlier. Its approach to address needs based on profession or sector provides an important model for other initiatives.

Another group with an unusual, and perhaps replicable focus, is the Gambia Physical Disability Sport Association. This group is unique as it is one of only three sport initiative-related organizations in our data set. The Gambia Physical Disability Sports Associations is a local civil society organization that represents young, physically challenged people and is committed to advocating for recreational programs and facilities. Lastly, the Future Stars Self-Advocacy Organization in Myanmar is another interesting civil society organization. This organization is unique because it aids the rural population of Myanmar specifically. This organization advocates for the self-advocacy of people with disabilities to independent living, legal participation, and education for people with disabilities in rural Myanmar. Given the regional disparities many countries noted, with disability more prevalent in rural and remote areas, this kind of regional focus may also be a model for other countries and regions.

#### **Impactful Organizations**

Several organizations stand out as making a significant impact within their country. Handicap International is one major organization that is involved in numerous countries and has made impactful differences in disability rights activism. For example, in Benin, a country with few civil society partners, Handicap International is heavily involved. This group works to improve the vocational and economic inclusion of people with disabilities in Benin through awareness-raising, training, and advocacy. They support the creation of inclusive businesses and develop guidance and financial support mechanisms to promote access to employment for people with disabilities. Specifically, they work with the authorities, companies, and training centers to facilitate the participation of people with disabilities in the political debate and to support advocacy actions aimed at securing their inclusion in the world of work. In addition to Benin, Handicap International works in the Central African Republic. There, Handicap International largely focuses on setting up orthopedic centers and on training medical staff to be more supportive towards people with disabilities. In more recent times, they have set up more rehabilitation centers and have sought to improve communication between the Central African Republic and foreign investors so that they can reap the benefits. Handicap International is also present in Comoros, Liberia, Senegal, and Sierra Leone. The Handicap International website then also names themselves as a civil partner in Myanmar, Nepal, Pakistan, the Philippines, Sri Lanka, Thailand, and Vietnam.

In addition to Handicap International, other organizations that are making substantial progress, specifically in terms of disability rights for women and children, are the Gambia Federation of Disabled, Gambia Organization of Visually Impaired, Gambia Association of Difficulty in Hearing, and Gambia Association of Physical Disabled and Disabled Peoples' Organization, all of which are noted in the Gambian report submitted to the CRPD. Many of these organizations are particularly successful working towards more suitable education for children with disabilities. According to the report to the CRPD, "30 participants from government departments and NGOs working with girls education and children with disabilities, to promote the educational inclusion of these populations" (The Gambia CRPD country report, 10). In addition, "In the Greater Banjul area, three special schools serve children with severe visual impairments, hearing impairments, speech disorders and learning difficulties. Students with less severe disabilities are mainstreamed into basic and secondary schools. In schools where these students are integrated, teachers have been trained in the special skills needed to include them" (66). Also, "There are three recognized specialized schools for persons with disabilities: St. John's School for the Deaf, Methodist Special School for children with Learning Difficulties and GOVI resource center providing an education service for the visually impaired" (CESCR Report, 20).

There are many civil society organizations that are doing impactful work in terms of combating stigmas and empowering people with disabilities. Many organizations specifically focus on empowerment through advocacy and education. One of these is Nepal Association of the Blind (NAB). NABs mission is "empowering the blind and partially sighted person through advocacy, capacity building and practical work so that their rights will be fulfilled and living conditions improved." NAB has 7 province committees, 52 district branches, 30 municipal branches and 3,000 members across the country. Somali Disability Empowerment Network (SODEN) is another organization doing important work to support those with disabilities and enable them to participate in social, professional, and economic and political life within Somalia. SODEN strives to create awareness around social issues and rights of people with disabilities through advocacy, education and empowerment, humanitarian aid programs, and legal aid. Uganda Society for Disabled Children is another civil society group that has focused on assisting children with disabilities mainly through raising public awareness about disability and advocating for change. They have assisted over 250,000 children with disabilities in their rehabilitation.

Stigmatization around disability is one of the main barriers persons with disabilities face in LDCs. Progress can not be made in these countries until everyone sees disabled persons as equal and important members of society or there are sufficient protections for them to exercise their rights.

The Rwanda Union of the Blind (RUB) is one organization in Rwanda with the mission of breaking down the strong stigma around blindness. RUB helps shift the narrative around the needs of blind people in Rwanda. Before RUB, there was a widespread belief that a blind person in the family was an embarrassment or curse and that blind people were the poorest in society. RUB helped educate others about the potential, needs and aspirations of visually impaired people and foster attention and appreciation for them. OneFamilyPeople is also doing important work in combating the stigmatization around disability. One of the greatest barriers for people with disabilities in Sierra Leone is prejudice and marginalization. OneFamilyPeople tries to combat this through education and advocacy as well as improve the overall standard of living for people with disabilities through economic power and health. Zanzibar Association of People with Developmental Disabilities (ZAPDD) also addresses the marginalization of people with disabilities within the social system. ZAPDD conducts awareness building campaigns in order to address the inhumane treatment of persons with disabilities.

Another way civil society organizations make an impact in their country is through coalition building. Uganda has multiple civil society organizations like the National Union of Disabled Persons of Uganda (NUDIPU). This is an umbrella organization that advocates for the inclusion of persons with disabilities and their concerns in the mainstream development process. The Tanzania Federation of Disabled People played a large part in advocating for the ratification of the UNCRPD as well as influencing the nomination of 20 persons with disabilities to the assembly. They have strong ties to the government of Tanzania as well as to other organizations within the country. Coalition building within their country is a key indicator of their success, as well as the ability to navigate the country's political climate.

## Conclusions

Ultimately, civil society partners and organizations play a critical role in the development of disability rights around the world. While our data finds trends in organizations for women, children, those that are blind, and those that are deaf, these partnerships span across countless areas of interest. Many Of the impactful organizations have used methods such as advocacy, education, coalition building, and fighting the stigmatization of persons with disabilities in order to make progress in the field of disability rights. These organizations help to advance community interests and fulfill international obligations.

#### SECTION IV: CIVIL SOCIETY AND OTHER INITIATIVES FOCUSED ON YOUTH WITH DISABILITIES

The LDCs, comparatively, typically lack the resources to provide widespread protections for people with disabilities. The question remains: How can they improve? Youth-centered activism is just one possibility to advance and promote disability rights in the LDCs and around the world. The CRPD and theoretical frameworks concerning disability rights generally agree that people with disabilities have the most authority to speak on disability topics as demonstrated by the slogan "nothing about us, without us" (Megret 2008, 509). Given that children and adolescents are not exempt from disabilities and there has been an upward trend of youth activism, it makes the most sense that youth with disabilities have high potential to make positive change in LDCs. This section highlights the countries who have notable efforts of youth activism, particularly unique efforts, countries who have been offered a lending hand by international organizations to create youth activism programs, and lastly, countries where we saw little evidence of youth disability activism or rights organizations.

Some countries have demonstrated a level of attentiveness to the rights of people with disabilities which seems to promote further and more unique activism in specific communities, such as youth with disabilities. For example, look at South Sudan and their "Young Voices Project" which is a podcast that aims to highlight people living in the country and the hardships they endure. Podcasts especially have been growing in popularity in recent times as well, and they are relatively accessible since tuning in can be done via radio or on the internet and they can reach those who lack literacy skills. Through a podcast series, one is able to highlight issues and educate the public and empower followers all at once. Moreover, activism in the form of podcasts appears to be growing in popularity and is proving to be effective within the youth today (Scheve 2020, 1). In Tanzania, the Youth with Disabilities Organization (YoWDO) is another organization where young disabled people empower and teach members on relevant and self-improving topics such as leadership skills and climate resilience. Having an organization being founded and run by young disabled people seems particularly valuable in increasing participation and prioritizing the needs of members. This group's mission is valuable compared to other groups because they seek to provide services and knowledge that goes beyond a simple project, but tools that can be widely used to enrich people's lives. Topics they address include how to better understand the economics of their country, business management, and advocating for changing economic policies to better suit the disabled community.

Another form of youth activism among the disabled community is seen in sports. Because of the importance of sports amongst youth, promoting the inclusion of persons with disabilities in athletics can contribute to a larger accepting and accommodating environment. The Special Olympics funds organized sports competitions for disabled people in many major sports. Countries with active Special Olympics range from Burundi and Comoros, to Senegal and Mauritania. There are currently over 5.5 million athletes participating in the Special Olympics worldwide with over 1.1 million coaches and volunteers as well (Special Olympics 2020, 1). In countries such as The Gambia there are additional organizations that target the youth in particular like the Gambia Physical Disability Sports Associations (GODA), where they advocate for the construction and maintenance of recreational facilities. This is done by connecting many other disability groups together under an umbrella group to better address and fund projects. Funding for these initiatives may come from the national government or private or NGO donors.

The country reports for Bhutan, Central African Republic, Chad, Eritrea, Ethiopia, Guinea-Bissau, Haiti, Lesotho, Madagascar, Malawi, Myanmar, Nepal, Niger, Sao Tome and Principe, Solomon Islands, and Tuvalu did not include youth-centered organizations focused on disability rights.

We hope the United Nations continues to support implementation of the principles of the CRPD with a particular focus on children and adolescents in the "fight for rights." Both government leadership and civil society are needed to advance the rights of disabled people, and youth can help lead those efforts.

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