

## Civic Update Disability Inclusion

Citizen Participation & Inclusion Team | October 2019



*“Live as We Live” event participants holding Wasool Signs, Libya (Credit: NDI)*

The World Health Organization (WHO) estimates 15 to 20% of the world’s population (approximately one billion people) as having a disability.<sup>1</sup> Persons with disabilities (PWDs) are the world’s largest minority group, with disability rates steadily increasing due to an ageing population, conflict, and a rise in chronic health conditions. The disability community remains largely excluded from public life and is underrepresented in parliaments and political parties. Stigma and stereotypes, including the belief that PWDs are incapable of contributing to society, continue to present significant barriers to PWDs exercising their rights, including the right to participate politically. NDI has worked with the disability community for over 25 years, supporting PWDs to engage politically and become full members of society with the rights, responsibilities, and respect afforded all citizens. The inclusion and political participation of PWDs and disabled persons organizations (DPOs) helps them access new political relationships and spaces, resulting in increased visibility and a greater ability to challenge stereotypes and reduce bias and social stigma lying at the root of discrimination and exclusion. Additionally, inclusion of PWDs helps ensure broader development initiatives take disability priorities into account.

## State of Disability Inclusion

PWDs represent a diverse group and each person's experience varies based on their interaction with their social environment. Often the definition of a PWD is narrowed to "classic" disability groups, described by the WHO as those with visible or sensory disabilities.<sup>2</sup> However, the community also includes people with invisible disabilities, such as those born with autism or older generations debilitated by arthritis or dementia. Within the disability community, many people experience intersecting forms of exclusion based on other identity factors. For instance, the prevalence of disability is higher among women and they also experience higher rates of violence. According to the 2018 UN Report on Disability and Development, data shows "extremely low" participation and representation of women with disabilities in political leadership roles and low representation of women through national mechanisms on disability matters.<sup>3</sup> Likewise, persons with albinism living in Africa experience high levels of violence due to traditional beliefs and they often are not represented by disability rights organizations because of the misconception that they do not have a disability. People with psychosocial or developmental disabilities face limits placed on their rights, with over 85% of UN member states having some type of legislation limiting voting rights for this community and one third of member states denying their right to vote.<sup>4</sup>

The disability community has organized itself to deal with all forms of exclusion and the global movement has made progress in recent years.

Through collective efforts of DPOs, governments, international organizations, and donors, the movement has begun to change the narrative from PWDs as objects of charity to being active, engaged members of society. To this end, the 2006 adoption of United Nations Convention on the Rights of PWDs (CRPD) created the first international treaty setting standards to promote, protect, and ensure the full and equal enjoyment of human rights and fundamental freedoms by all PWDs. The CRPD marked a high point in collective action and collaboration across disability communities and country contexts.

The CRPD plays a pivotal role in changing social norms, raising awareness for disability rights and linking those rights with achieving a more sustainable future. During the creation of the 2030 Sustainable Development Goals (SDGs), the International Disability Alliance and International Disability and Development Consortium successfully lobbied for the representation of PWDs in the SDGs.<sup>5</sup> These efforts ensured that the SDGs explicitly promote the social, economic, and political inclusion of PWDs in achieving the criteria, "leave no one behind." The CRPD also helps ensure that disability is considered and addressed when responding to ongoing and emerging global challenges. In 2019, the United Nations Security Council unanimously passed the first resolution on protecting people with disabilities in conflict.<sup>6</sup> The resolution urges member states to ensure access to justice, unimpeded humanitarian assistance, and meaningful participation of PWDs and DPOs in conflict prevention, reconciliation, and peacebuilding.

### The Social Model

NDI utilizes the CRPD definition of disability which states that "PWDs include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others." The CRPD definition represents a shift in thinking around disability from the "charity" and "medical" models, to the "social" model. The social model indicates that disability sits at the intersection of environmental, institutional, and attitudinal barriers and exists, not because of impairment, but as a result of the limitations and barriers posed by society. The social model shifts the responsibility of inclusion from the individual to society, underscoring the concept that barriers imposed by society are the true source of disability.

CRPD [Article 32](#) recognizes the inherent value of mainstreaming disability rights and participation in development programs, and international donors have taken measures to address disability inclusion within their respective strategies. The United States Agency for International Development has a [Disability Policy](#) and [approach](#) focused on the development of targeted, inclusive programs for PWDs and mainstreaming the inclusion of PWDs in all programs. Additionally, the US Department of State's Bureau of Democracy, Human Rights, and Labor, has staff specifically supporting international disability rights and monitoring the inclusion and protection of PWDs' rights in programs. The Department for International Development (DFID) released their [strategy on disability](#) in 2018, building on the momentum of the 2018 Global Disability Summit, by ensuring "people with disabilities are consistently and systematically included in international development and humanitarian assistance."<sup>7</sup> DFID also released a [strategic plan](#) and comprehensive set of [inclusion standards](#) that prioritize PWDs in all programmatic efforts.

Despite progress, PWDs remain largely excluded from public life. Their persistent exclusion stems from four types of barriers:

**Attitudinal:** negative perceptions and stereotypes, cultural beliefs, and misinformation or lack of knowledge about disability. **Response:** In Kenya, a group of cross-sectoral DPOs and civil society organizations, with NDI technical support, is working to alleviate the attitudinal barriers persons with albinism face through collective advocacy campaigns and awareness raising to dispel traditional beliefs and negative perceptions.

**Environmental:** physical barriers that prevent access and equitable participation, including inaccessible communication systems that limit access to valuable information, knowledge, and opportunities. **Response:** In Colombia, the electoral council now requires political parties to include sign language at public events and in their publicity. To support these efforts, NDI



Logo of NDI partner: Albinism Society of Kenya

is working alongside a DPO to develop a database of interpreters to share with political parties to ensure compliance with this requirement.

**Institutional:** laws, policies, and practices that discriminate against PWDs and prohibit participation, including laws that do not adequately address the needs of PWDs, which deliberately or inadvertently facilitate exclusion. **Response:** NDI built the advocacy capacity of Mexican DPOs to monitor the government's compliance with the CRPD.

**Data:** a significant lack of data, disaggregated by disability, undermines PWDs' ability to advocate for their rights and makes it difficult for governing bodies to formulate evidence-based decisions about disability policy, programs, and budget allocations. Although some data exists, the gaps are particularly detrimental for vulnerable groups within the disability community, such as migrants and refugees<sup>8</sup> as well as indigenous PWDs.<sup>9</sup> **Response:** NDI is drafting a disability-inclusive manual with frameworks and guidelines to help teams effectively design, monitor and evaluate democracy assistance programs with a disability inclusive lens.

## NDI’s Approach to Disability Inclusion

[Article 29](#) of the CRPD focuses on participation as a means for advancing inclusion and delineates the rights of PWDs to participate in both political and public life, including accessible voting materials, the right to a secret ballot, and to organize in the form of DPOs.<sup>10</sup> NDI supports DPOs to increase their opportunities to participate equitably in civic and political life, change social norms around political inclusion and collectively advocate against continued marginalization and for disability rights. In 2018, NDI signed a commitment at the DFID Global Disability Summit, agreeing to advance efforts to mainstream the participation of PWDs and DPOs throughout all NDI programs as well as expand PWDs access to political life, increase PWDs positive visibility, and support policies that prioritize PWDs. This commitment also requires the inclusion and active involvement of PWDs in program design, implementation, and M&E and a consideration for reasonable accommodation in all program budgets. Reasonable accommodation is defined as appropriate or necessary adjustments that give PWDs an equal opportunity to participate alongside other citizens.

## Do No Harm (DNH) and Nothing About Us Without Us

Do No Harm acknowledges that external interventions, like NDI programs, interact with societal norms and existing vulnerability factors, requiring any intervention to be sensitive to the local context. In order to mitigate harm, NDI partners with local DPOs to assess the history and current state of disability rights and DPO relationships within the country. This analysis helps ensure interventions do not exacerbate conflict, create unnecessary risks for partners or deepen discriminatory power imbalances. Grounded within DNH is the understanding that PWDs are experts regarding their lived experiences, and therefore know what’s best for them and their community. NDI also practices “Nothing About Us Without Us” which is a rights-based approach to development, supporting disenfranchised communities to claim their agency, build political power, and choose their own priorities. NDI operationalizes this principle by consulting members of the disability community and always conducting programs in partnership with local DPOs.

### People First and Rights-Based Language

Utilizing the appropriate language when communicating about disability or referring to PWDs shapes norms and attitudes, demonstrates respect, and helps avoid perpetuating negative stereotypes. NDI uses people-first language which emphasizes the person before the disability. An exception to this rule is the term “disabled persons organization,” used to describe organizations comprised of and run by PWDs. Below are examples of appropriate language and when it doubt, it is always best to ask.

Instead of:	Say:
Disabled people/person, handicapped, special	Persons/people with disabilities
Cripple or invalid	Physical disability
Retarded or mentally handicapped	Intellectual or developmental disability
Crazy, insane, mental disorder	Psychosocial disability
Hearing impaired, “the deaf”	Deaf, person who is deaf
Visually impaired, “the blind”	Blind, person who is blind/has low vision
Able-bodied	Non-disabled

## Dual-Track Approach

NDI's dual-track approach to disability includes **mainstream** and **targeted** programs.

**Mainstream** programs involve PWDs and DPOs working alongside other community members and encourage increased outreach from government institutions, elected officials, and political parties. Mainstreaming PWDs into programs challenges stigma around political participation and reinforces norms of inclusion.

**Targeted** programs support PWDs and DPOs to address exclusionary institutions, laws, and processes. Targeted programs can include assisting PWDs or DPOs with advocating for legal reforms or persuading the government to implement international agreements like the CRPD. Targeted programs also provide PWDs and DPOs with safe spaces to learn from each other, establish local or national networks, and organize around issues unique to their community.



*DPO leaders participate in a CSO Roundtable in The Gambia (Credit: NDI)*

## Constitutional Reform in The Gambia

A twenty-year authoritarian regime ended when The Gambia successfully held democratic elections in 2016. Following the transition, the newly elected President Adamu Barrow undertook several reform processes, including a multi-stage constitutional review. To help support the constitutional review process, NDI began a program funded by the National

## Inclusive Elections

The rights of PWDs to vote and hold elected office is protected by the CRPD, however, the disability community continues to face major barriers, such as inaccessible polling stations, lack of accessible information on party platforms, and laws requiring a candidate to be both physically and mentally fit, which is often utilized to restrict participation of candidates who are disabled. However, including PWDs and DPOs as election observers, poll station workers, election administrators, candidates, and providers of voter education provides a unique opportunity to challenge common stereotypes and sustain participation.

In Afghanistan, NDI is assisting Afghan Amputee Bicyclists for Rehabilitations and Recreation (AABRAR) to mobilize PWDs in several provinces to serve as pre-election, election day, and post-election observers. In addition to participating as observers, AABRAR collected accessibility data during the September 2019 elections and will provide recommendations to ensure greater accessibility on election day. In Mali, the Malian Federation of People with Disabilities (FEMAPH), in partnership with other CSOs, is conducting inclusive “get out the vote” and voter registration activities. As a member of the Public Engagement Charter for Emergence (CEPE), the coalition’s inclusive strategy includes organizing voter engagement campaigns that provide information through a variety of mediums such as posters with written instructions, pictograms, and sign language.

For more on inclusive elections, refer to NDI’s [Equal Access - How to Include Persons with Disabilities in Elections and Political Processes](#). The manual is available in eight languages and provides comprehensive guidance on the inclusion of PWDs in elections and other democratic processes.



*IFA, Executive Director Grace Jerry being interviewed during a pre 2019 election rally in Abuja, Nigeria  
(Credit: NDI)*

Endowment for Democracy (NED) in 2017. Results from the first-ever countrywide [public opinion research](#), conducted by NDI, demonstrated that Gambians felt positively about the direction of their country, but remained unclear about the roles they could play in reform processes. To address this challenge, NDI engaged with The Association of Non-Governmental Organizations in The Gambia (TANGO) to support CSOs in ensuring an inclusive and citizen-led constitutional reform. As the Constitutional Review Commission (CRC) entered its final outreach stages, NDI conducted an assessment in May 2019 to evaluate civil society's engagement. The assessment found the participation of PWDs to be largely absent. This finding prompted NDI to convene a workshop for the Gambia Federation of the Disabled (GFD) and representatives from fourteen DPOs for a workshop to analyze the constitution and identify common concerns. The workshop utilized sign language interpreters and covered expenses for caregivers to ensure all DPO leaders could attend and participate. Collectively, the group drafted a position paper for submission to the CRC and agreed on next steps to address identified issues. DPO leaders also participated in a broader civil society

roundtable where they raised disability issue, networked with other segments of society, and devised ways to work collectively on constitutional reform and disability issues. Since the meeting, the GFD and DPO have engaged with the CRC to advocate for an inclusive constitution, met with the electoral commission to discuss election accessibility, and engaged with high-level decision makers to gain a commitment to pass the Disability Rights Bill before 2020.

## **Building CSO Capacity in Nigeria**

As part of an electoral empowerment in Nigeria, NDI partners with DPO Inclusive Friends Association (IFA) to advocate for greater voting accessibility for PWDs. In 2016, IFA, in partnership with other DPOs, undertook the first ever PWD-led election accessibility audits in Nigeria during the off-cycle gubernatorial elections in Edo and Ondo States. The audits assessed the availability of features such as handrails, ramps, Braille or tactile ballots, written voting instructions, and sign language interpreters. IFA will conduct a second round of accessibility audits during the November 2019 gubernatorial elections in Kogi and Bayelsa



*July Workshop for PWDs in Libya (Credit: NDI)*

States to measure progress in polling unit accessibility since the 2016 audits and to further document the voting experiences of PWDs for ongoing advocacy efforts.

Under their campaign #AccessNigeria: Disability Votes Matter, IFA has engaged in sustained advocacy with the Independent National Electoral Commission (INEC) to draw attention to election barriers for PWDs and presented a set of accessibility recommendations, including amending the Electoral Act to make Braille or tactile ballots mandatory, and ensuring funds in the national budget for accessible electoral materials, such as sign language interpreters and accessible voting cubicles. In the fall of 2017, IFA presented their audit report to key stakeholders, including the INEC chairman who publicly committed to supporting IFA's suggested accessibility reforms and confirmed INEC's recognition of disability rights as fundamental to Nigeria's democracy. As a result of their campaign, INEC introduced written election instructions for voters who are deaf or hard of hearing and a Braille ballot guide for voters with visual impairments to cast a confidential ballot. IFA also contributed to collective efforts by Nigeria's Albino Foundation for the introduction and retention of magnifying glasses to assist voters with low vision to vote unaided.

In addition to their partnership with INEC, IFA contributed to advocacy efforts targeting the government of Nigeria to pass and sign a national disability bill, demonstrating their capability to contribute to inclusive advocacy efforts beyond electoral reform. Over the last three years of collaboration and technical guidance, IFA has grown from a regional organization based in Plateau State to a national organization with its headquarters in the capital. IFA is now positioned as a nationally recognized organization and an authoritative voice on disability rights, developing their leadership capacity to positively contribute to the sustainability of current and future campaigns.

## **Strengthening PWD Advocacy and Engagement in Libya**

During times of conflict or closing civic space, DPOs can serve as vital partners. DPOs are often viewed as politically non-threatening compared to other CSOs and are usually able to continue their efforts despite changes in the political climate. To maintain civic space in Libya, NDI is working to build the capacity of DPOs to increase their organizing and advocacy through training and technical assistance under a USAID-funded program. Through the program, NDI conducts workshops for DPOs on campaign strategy and tactics and outreach to

policymakers. NDI has worked with DPOs in Libya since 2014 and has helped build their capacity to advocate for greater accessibility to municipal and national buildings and universities. NDI's support to disability groups includes facilitation of meetings with local policymakers and training on proposal development, media campaigns, and stakeholder engagement. NDI consulted DPOs to identify accessible training spaces and accommodation. Through these programs, DPOs are implementing advocacy campaigns across Libya for improved accessibility in university and public buildings, as well as reducing barriers for PWDs to be accepted into higher education institutions. As a result of NDI's support, DPOs in Libya, to date, have successfully advocated for the adoption of the CRPD, secured an official order from the Ministry of Local Government mandating necessary improvements to commercial spaces so they are accessible, and hosted public events to bring awareness to the issues PWDs face in Libya.



*Logo for NDI Partner: Ushiriki Tanzania Coalition*

## Coalition Building in Tanzania

Despite national legislation and policies directed at accommodating PWDs in Tanzania, such as the Persons with Disability Act No. 9 of 2010 and various provisions within the Constitution,

PWDs face continued barriers that hinder active political participation including accessibility challenges, social marginalization, stigma and discrimination. To promote increased inclusive citizen engagement and oversight of political and electoral processes, NDI is implementing the *Tushiriki Pamoja* (Participate Together) program. A key component to this program is establishing and building the capacity of a coalition comprising more than 20 CSOs called *Ushiriki* (participate) Tanzania (UT or the Coalition), which represents women, young people, human rights defenders, and DPOs including the Tanzania Federation of Disabled People's Organizations and the Organization of Women With Disabilities (Zanzibar). UT is working to increase inclusive political participation of women, youth, and PWDs, as well as influence electoral policy and frameworks for credible elections. The Coalition has utilized the diversity and expertise of their members to rapidly respond to policy changes and provide important recommendations to the government, in particular, the Ministry of Local Government, on accessible elections in preparation for the November 2019 local government elections. In addition, UT is collectively advocating to the National Electoral Commission to ensure voter information and education is inclusive of all voters and to improve the accessibility of polling stations as well as provide training to security forces to ensure the safety of all voters on election day.

## Influencing Local Decision Making in Kyrgyzstan

Kyrgyzstan continues to represent the most democratic political system in Central Asia and hosts a diverse and active civil society. However, CSO representation and citizen engagement outside of the capital remains muted, with little understanding by citizens of their roles and responsibilities as citizens in a democracy and how to effect change. To address this, NDI implemented the Citizens in Action program to build the capacity of community members to organize around issues of local concern and engage in constructive dialogue with local government to address these issues. Between 2016 and 2018, the Institute trained more than





*Constructing fencing the electricity power transformer in Kok-Zhar, Kyrgyzstan (Credit: NDI)*

1,000 individuals to identify and prioritize specific community needs, map decision-making power in their locality, navigate the budget process, and mobilize fellow citizens to advocate for change with the participation of community members. In Kok-Zhar, a district outside of Bishkek, a participating Community Organizer (CO) surveyed his neighborhood and identified disability safety and accessibility as a priority concern for citizens. NDI trained the CO and local citizens, mostly PWDs, on advocacy and local decision making processes. Following the trainings, community members held meetings with decision makers, lobbied local councilors, submitted letters to the Mayor of Bishkek, and engaged with private sector stakeholders. As a result, community members successfully lobbied local government to adjust a bus line that has allowed over 200 PWDs access to essential public transportation and to construct a safety fence around a generator for persons who are blind. Not only did community members achieve their goal of expanding access for PWDs, the process initiated a constructive relationship between community members and the local government in Kok-Zhar. The community members trained by NDI have continued to mobilize citizens and work with government to solve issues beyond donor support. Since this initial achievement, the same group successfully lobbied government for road repairs and the construction of an education center for children with disabilities.

## Considerations

As demonstrated by the program examples above, there are many ways NDI engages with PWDs and DPOs to improve their political participation and inclusion. Increasing political inclusion, a cross-cutting institutional objective, is not always an expressed priority in funding opportunities or solicitations. A 2015 study, conducted by the United States International Council on Disabilities revealed that disability inclusion only occurs when there is specific, detailed language in the solicitation mandating their inclusion. Additionally, only 20% of solicitations reviewed required PWD inclusion or *meaningful* inclusion in programming.<sup>11</sup> Although donors increasingly include requests for greater inclusion or a focus on marginalized communities, the specific communities are often undefined and overlooked which perpetuates a cycle of underrepresentation and marginalization, especially in development interventions.<sup>12</sup> Ensuring that PWDs are considered and included during the proposal design process as well as mainstreamed into programs is imperative considering the decline in funding for programs specifically targeting the rights of PWDs.<sup>13</sup>



*Reasonable Accommodation Grid  
Credit: <http://bit.ly/2AWLAcM>*

NDI can address gaps in programs by being more intentional about which segments of the population are prioritized. Proposals should be explicit, whenever possible, about the intended participants and seek to include partners that demonstrate NDI's commitment to inclusion across demographics. In addition, NDI should prioritize mainstreaming PWDs and DPOs whenever possible into programs, which will bring a different and diverse perspective to programs and encourage partners, decision makers, and civil society leaders to be more inclusive in their efforts.

NDI has an opportunity to be more proactive regarding the inclusion of PWDs in the following ways:

- 1. Mainstream reasonable accommodation** into program budgets. Reasonable accommodation includes hiring a sign language interpreter for an event or supporting a caregiver to attend a training. Programs should always budget for reasonable accommodation, ensuring funds are available to support equitable participation.
- 2. Identify appropriate technology** that already exists and is being utilized by the disability community or new technology that may be useful for campaigns. Technological advances have made it easier for PWDs to participate in civic and political life, reducing barriers to communication and enabling PWDs to receive information in the format they prefer. Social media can also serve as an important platform for organizing, while mobile phones are useful for both sharing information and as assistive devices.
- 3. Prioritize information accessibility** so PWDs are aware of current political issues, political party platforms, where and how to vote, or how to run for office. The majority of communication methods, both digital and traditional, are not accessible. When developing information materials consider utilizing image descriptions for photos, ensuring all videos have captions and

readable transcripts, utilizing [Easy Read](#) for physical documents, or encouraging political parties, MPs, and the media to use sign language interpreters.

- 4. Improve data collection and disaggregation.** [The Washington Group Questions](#) attempt to address data collection challenges by assessing issues of core functioning to identify barriers that inhibit people's participation.<sup>14</sup> The Questions have been incorporated into multiple census in Africa, Asia, and the Pacific, providing countries with more reliable data. Participatory research can also be used to create opportunities to connect with DPOs and develop a shared purpose and goal around data collection.
- 5. Strengthen regional disability federations and increase sharing among networks.** Federations often serve as the voice of DPOs and building their capacity can ensure sustainable collaboration and action within the disability community after a program has ended. DPOs also seek opportunities to learn from each other and share different approaches. Increasing learning opportunities is important for strengthening DPO networks, building sustainable linkages, and helping DPOs work together towards common causes.
- 6. Consider intersectionality** during each stage of our work. This requires moving beyond traditional frameworks where identity is separated into isolated categories. Instead, it involves a better understanding of how the unique experiences of different identities influences the lives of PWDs. Additionally, intersecting systems of oppression can lead to compounding marginalization for very specific populations, such as ethnic and religious minorities with disabilities, indigenous people with disabilities, and women with disabilities. Diversity within the disability community can provide opportunities for greater collaboration and empowerment for those who experience a greater degree of marginalization.

## Additional Resources

### [CRPD Advocacy Action Toolkit](#)

The World Bank [Disability Inclusion and Accountability Framework](#)

OSCE [Guidelines on Promoting the Political Participation of PWDs](#)

CBM [Advocacy Toolkit for Disability Mainstreaming](#)

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