Disability Inclusion Helpdesk, June 23

Evidence digest focus issue: Organisations of Persons with Disabilities around the World

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Guest blog: Sightsavers' mapping of organisations of persons with disabilities

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To introduce this evidence digest, we spoke to Diane Kingston OBE, human rights defender and international development specialist. Diane is the Global Technical Lead on Disability Inclusion and Mainstreaming in Sightsavers and has been leading Sightsavers' work to develop a global dashboard of organisations of persons with disabilities (OPDs).

How did you become involved in mapping OPDs?

Sightsavers has been on a process of understanding how to engage with OPDs in different contexts for some time.
When I first started work in this area, engagement with OPDs was done well in some contexts but tended to more ad-hoc and focused on working with umbrella OPDs. When we began our mapping project, we started with trying to understand what already existed. We spoke with the International Disability Alliance (IDA) and Women Enabled International and did a trawl of existing resources. Our desk review found a strong pattern of development actors only consulting umbrella OPDs when seeking to engage with people with disabilities. However, we know that the OPD landscape is a lot more complex. We decided to pick 16 countries where we had existing social inclusion programmes and conduct a more in-depth mapping process, engaging with umbrella organisations but going beyond these to consult with organisations of women with disabilities, impairment specific OPDs, and significant individuals in the disability movement who are not members of OPDs.

We have developed a dashboard that contains contact information for OPDs but also information on the subjects they work on and the types of work they do amongst others. Over 600 staff in Sightsavers have been offered training on how to use the dashboard.

What challenges did you find when conducting your mapping exercise?

The global OPD landscape is always changing, so it is hard to have an up-to-date directory. We know that OPDs are often under-resourced, which forces some to shut down. New OPDs are also frequently established but can be difficult to identify, especially if they are small, community-based, or don't have an online presence.

Identity politics is an important consideration when mapping OPDs. There are some organisations that we as Sightsavers might consider to be an OPD but the organisation itself wouldn't, which can make them more difficult to identify or engage with on disability rights. This includes organisations that focus on conditions that usually affect older people, such as Alzheimer's and dementia.

We also found that there are many people with disabilities who are not members of OPDs. In Cameroon and Senegal, among people with disabilities, only 2.9% and 6.9% were a member of an OPD respectively. Whilst we found this shocking in some ways, in others it was obvious – I have a disability but I'm not a member of an OPD. I have been in meetings of global disability experts where only a third of people with disabilities were members. There are lots of reasons why this happens, sometimes there are no OPDs nearby, people aren't aware of them, or people might not have time or be politically minded.

There is a disconnect between some groups and mainstream OPDs. In our research we found that OPDs were often led by men. Whilst some women report progress and hold positions of power in umbrella OPDs, the majority of women we spoke to we led to start their own OPDs or join up with women's rights organisations (WROs), citing frustration over gendered power dynamics, discrimination and harassment, and a lack of consideration of issues they prioritise. LGBTQI+ people with disabilities face exclusion and harassment. We also found that people with impairments that are less apparent, particularly people with mental health conditions and/or psychosocial disabilities, are less likely to participate in and lead umbrella OPDs due to stigma and facing greater barriers to education and employment than other impairment groups.

Increasingly, I also find that young people with disabilities are less likely to be engaged with OPDs. There is digital gap in communication methods, particularly due to the different ways generations use technology. As we improve the way that we engage with OPDs, it is important for us to remember that OPDs do not represent all people with disabilities.

What advice would you give to organisations or donors looking to meaningfully engage with OPDs?

Before we publish the dashboard, we are verifying the information and embracing the internal recommendations we developed while conducting the mapping. Some of these recommendations are useful for organisations more widely:

- When identifying OPDs to work with, choose those **that represent the broadest range of disabilities**; or if that is difficult, augment your partnerships with OPDs that work with

those at more at risk of exclusion such as organisations of women with disabilities or those representing people with intellectual disabilities.

- **Identify strategies that will enable you to bring the voices of people with disabilities in all their diversity to your work.** This may include holding specific focus group discussions on a topic or setting up an advisory group.

The latest evidence and guidance on Organisations of Persons with Disabilities around the World

Meaningful engagement

The International Disability Alliance (IDA) and NORAD produced a **discussion paper on OPD engagement** to unpack, frame, guide and incentivise engagement of OPDs in development and humanitarian action through the Global Disability Summit 2022. The paper explores OPDs' perceptions of their participation in decision making, finding that while OPDs are more consulted than before, levels of participation remain insufficient. It also uses case studies to unpack what OPD engagement means in practice, and to provide evidence on what works. The discussion paper is also available in **Arabic**, **French**, and **Spanish**.

In June 2023, the journal article **How representative are organisations of persons with disabilities? Data from nine population-based surveys in low- and middle-income countries** was published in Disability & Society. The article explores the extent to which people with disabilities in low- and middle-income countries are aware of, and members of, OPDs. Using data from nine population-based surveys, the researchers found that about a third of people with disabilities are aware of OPDs and fewer than 15% are members. Awareness and membership was generally lower amongst older people with disabilities, women, people with difficulties communicating, remembering and with self-care, and people living in poverty. The article includes a discussion of implications of the research for policy and practice, including that the priorities of some groups of people with disabilities may be missed if OPD membership is not representative.

In June 2023, the OPD Partnership Task Group of the International Disability and Development Consortium organised a side-event at the 16th session of the Conference of States Parties to the UNCRPD on the **Meaningful Engagement of organisations of persons with disabilities (OPDs) and the inclusive processes for reaching under-represented groups of persons with disabilities in programming**. A recording of the event will be available shortly.

IDA published **"Not Just Ticking the Disability Box? Meaningful OPD Participation and the Risk of Tokenism"** in 2022. This new report presents the findings of the 2nd IDA Global Survey led by OPDs on their participation in decision making processes of governments, the UN system and funding agencies. This report provides a comparison against the baseline of the 1st Global Survey report - **Increasingly consulted, but not yet participating: IDA Global Survey Report on Participation of Organizations of Persons with Disabilities**.

Further analysis of the IDA survey results is contained in the journal article **Strengthening the Participation of Organisations of Persons with Disabilities in the Decision-Making of National Government and the United Nations**, published in Disabilities in 2021.

In February 2022, CBM UK published the report **"We have a key role now": Lessons learned from partnerships with organisations of persons with disabilities**. The report shares the outcomes of a listening exercise with 32 OPD partners in 14 countries which was undertaken as part of CBM UK and CBM Global's, commitment to building authentic partnership with, and accountability to, the Disability Movement. The report identifies eight steps for CBM going forward, including ensuring that people with disabilities set the agenda, increase funding, and model accessibility across all areas of work. CBM published a **blog** to announce the launch of the report.

In 2021, Leonard Cheshire produced a quick guide on **meaningful engagement with OPDs**. The guide provides examples of what meaningful engagement can involve, including participating in decision-making processes, promoting advocacy, working in programmes, reviewing materials, and assisting with the operation of the organisation. The guide closes by listing benefits of meaningful engagement for partnering organisations – such as providing credibility and legitimacy – and OPDs – such as influencing policies and programmes.

The World Bank published a **technical note on disability-inclusive citizen engagement** in 2022. It provides overarching guidance for World Bank task teams on how to support their government clients to meaningfully engage persons with disabilities and OPDs in providing feedback on World Bank Group operations. The note includes insights from World Bank operations, including that projects typically hold separate events or meetings with persons with disabilities, instead of making regular consultations disability inclusive.

In 2022, CBM published an **interview with disability activists** from the Ugandan Disabled Union, Downs Syndrome International, and Ugandan Federation of the Hard of Hearing. The interview covers the role of OPDs in advocating for the rights of all people with disabilities in Uganda.

OPD Directories

The following organisations have lists of their members: **International Disability Alliance**, and **Women Enabled International**. The **Disability Rights Fund** has a directory of organisations that have received grants.

Gallaudet University hosts a **directory of organisations of Deaf people** and schools for Deaf people around the world.

The International Organisation on Migration developed a **directory of OPDs in Iraq**. The directory is available in English and **Arabic**.

Guidance and toolkits

The Inclusive Futures programme produced a **guide to building successful partnerships between INGOs and disability organisations** in January 2023. The guidance draws on

three peer-to-peer roundtables with INGOS and OPDs from the Inclusive Futures consortium, where participants discussed their direct experience about what has worked well (and what hasn't) to build meaningful partnerships together for a disability-inclusive development or humanitarian project. Nine steps are identified including starting with shared vision and values, respecting OPDs as expert organisations, and sharing power, leadership, ownership and responsibility. **Easy Read** and **Bangla** versions of the guidance is available.

The Disability Inclusive Humanitarian Toolkit, produced by UNICEF, includes a **tipsheet on engaging with OPDs in humanitarian action**. The toolkit outlines key steps: (1) identify OPDs and informal group of persons with disabilities in your location, (2) ensure that OPD engagement reflects diversity, (3) agree with OPDs on the type of engagement, (4) facilitate ongoing engagement and consultation with OPDs, (5) appropriately resource OPD engagement, and (6) establish systemic engagement with OPDs including longer-term partnerships.

USAID published **Implementation Tips for USAID Partners** in 2020. The sheet covers how to identify OPDs, how organisations can work with and support OPDs, and how organisations can support OPDs to advance inclusive local development.

The latest evidence and guidance on disability inclusion: Other topics

General

A systematic review of **effectiveness of interventions for improving social inclusion outcomes for people with disabilities in low- and middle-income countries** was published in Campbell Systematic Reviews in March 2023. The review's findings suggest that various interventions to improve the social inclusion of people with disabilities have a significant positive effect. Interventions such as social and communication training and personal assistance led to significant improvement in the social behaviour and social skills of people with disabilities. Studies targeting broad-based social inclusion showed a large and significant positive effect. A moderate effect was reported from interventions designed to improve relationships between people with disabilities and their families and communities. However, authors encourage that the findings of this review are interpreted cautiously, given the low confidence in study methods, severe heterogeneity and significant publication bias.

The **UNPRPD Fund 2022 Annual Report** provides a comprehensive overview of the collective progress and achievements in supporting the implementation of the CRPD and disability-inclusive SDGs. It showcases inspiring stories, innovative approaches, and successful partnerships that are driving transformative change.

The Atlas Alliance published the report Tracking Disability Inclusive Development: making the most of the OECD-DAC disability inclusion policy marker in March 2023. This report offers a brief stock-take of how the marker has been used in its first four years and highlights four opportunities to build further on progress. The opportunities are (1) make full use of the

disability inclusion policy marker, (2) make full use of the disability inclusion policy marker results for learning, (3) drive up data quality, and (4) fine-tune the criteria for applying the disability inclusion policy marker. A recording of a seminar to launch the report, which has International Sign interpretation and captioning, can be accessed here.

Oxfam developed an **inclusive language guide**, which provides guidance on inclusive language on disability and physical and mental health, alongside guidance on language on gender justice, sexual diversity, women's rights, migration, race, power and decolonisation.

Hue published an **inclusive workplace toolkit**, which provides guidance on language, microaggressions and inclusive workplace practices and policies, in response to: racism, colonialism, queerphobia, transphobia, ageism, fatphobia, classism, sexism, ableism & neurodiversity.

Climate justice

CBM published a **discussion paper on climate change and disability** in June 2023. The paper explores whether the climate crisis impacts implementation of the Convention on the Rights of Persons with Disabilities (CRPD), looking at evidence in three countries: Bangladesh, Kenya, and Nepal. The paper found that with increasing costs of climate crisis, disability was not a key priority in any areas, including policy and finance allocation for the governments in each of the case study countries. In addition, the study found that OPDs and persons with disabilities are not systematically included or meaningfully consulted in budgetary decision making for policies, even those that specifically relate to persons with disabilities, both within and outside the context of climate change.

The Disability Inclusion Helpdesk published a query on **disability inclusion in climate justice frameworks and environmental and climate risk assessment processes**. Overall, the query found that disability inclusion is generally not addressed as part of climate justice frameworks, and no evidence was found of climate risk-assessments that incorporate people with disabilities. It concludes with key considerations for ensuring people with disabilities are included in analysis of risk and do no harm in climate, energy, and environment programmes.

Human Rights Watch published an article on the need for funding to **ensure climate action is inclusive of people with disabilities and older people during the monsoon season in Bangladesh**. Human Rights Watch conducted interviews with survivors of floods and disability rights organisations, climate change experts, local officials and aid agencies between August 2022 and May 2023. They found that the authorities had failed to deliver early warnings and adequate assistance with evacuation, shelter, health care, food, drinking water, sanitation, and hygiene, particularly to older people and people with disabilities. Most of those interviewed said they had no support from the government to reach safety and to access essential services, such as shelter, health care, and food assistance.

Data

The Disability Data Initiative published the 2023 **Disability Data Report**, which reviews trends in the availability of disability questions in population censuses and household surveys overtime and produces national and subnational disability-disaggregated statistics using census and Demographic and Health Survey data for 15 countries. Key findings include that about one in five datasets reviewed for the 2009-2022 period contain functional difficulty questions and that global trends suggest an increase in the share of datasets with the Washington Group Short Set of Questions in national censuses and surveys. Summaries are available in Easy Read, Arabic, Chinese, French, Russian and Spanish.

Employment

Light for the World published the report **Towards inclusion of persons with disabilities within BRAC's Skills Development Programme** sharing findings from their work with BRAC in Bangladesh from 2018-2023 to explore how BRAC could become a more accessible organisation. As part of the Inclusive Futures programmes, Light for the World supported BRAC to upgrade their ability to include persons with disabilities in their work and organisation. People with disabilities were hired as Disability Inclusion Facilitators to support learners with disabilities included in the STAR programme, one of BRAC`s main Skill Development Programmes which places young, disadvantaged learners in the workplace as apprentices, under the guidance and training of a master craftsperson. Learnings are presented per organizational domain: Governance, Programme Management Practices, Human Resources, Financial Resources, Accessibility and External Relations.

The Inclusive Futures programme published a s**elf-assessment tool to ensure economic empowerment programmes are meeting the expectations of young people with disabilities**, which was developed by young people with disabilities. The tool is open-source and freely available for anyone working in the development sector and economic opportunity or livelihoods programming to use. The tool considers three dimensions: (1) levels of participation, inclusion and safeguarding of youth with disabilities, and their representative organisations, in the design, delivery and evaluation of projects and programmes, (2) how well the capacity building functions align with the needs and expectations of youth with disabilities, and (3) to what extent programmes match the broader career aspirations of youth with disabilities.

The Inclusive Futures programme held an online panel event - **Be inclusive - employment and livelihoods** – in May 2023. Speakers from Inclusive Futures consortium partners including BRAC, Humanity and Inclusion, Light for the World and United Disabled Persons of Kenya shared experiences and lessons learned from adapting livelihoods programmes to be disability inclusive in Bangladesh, Kenya, and Uganda. Stefan Trömel from the ILO closed the webinar with a reminder that all mainstream economic empowerment programmes need to include people with disabilities. Captions and sign language interpretation are available.

Human rights, freedom and democracy

The Special Rapporteur on the rights of persons with disabilities submitted a report to the Human Rights Council on the **transformation of services for people with disabilities**. The Special Rapporteur outlines how traditional service and support models often perpetuate dependency and lack of agency by focusing on impairments and considering people with disabilities as passive recipients of care rather than taking a human rights approach. The report finds that a new philosophy of service and support is emerging and requires clearer articulation in law and policy. The report is available in official UN languages and **easy read** format.

LGBTIQ+ people with disabilities

Following the passage of the 2023 Anti-Homosexuality Bill in Uganda, EmbraceKulture, a organisation promoting the rights of children and young people with disabilities in Uganda, published the article **We Are All Human - Disability and Gay Rights Unite in Uganda**. The article highlights the intersections between LGBTQI+ and disability rights movements and gives examples of how the movements have supported each other. It closes with the following passage: "It is therefore our responsibility as advocates for the disability community in East Africa to join our voice with the LGBTQ+ community to achieve a more just and equitable society. It is up to all of us to speak out against discrimination and advocate for the rights of these marginalized groups. By working together, we can create a society that is inclusive and accepting of all individuals, regardless of their background or identity."

An **article on the 2023 Anti-Homosexuality Bill** published by Human Rights Watch explains how the legislation calls for the death penalty in certain circumstances, including for having same-sex relations with people with disabilities, thereby automatically denying persons with disabilities the capacity to consent.

Older people with disabilities

In June 2023, Human Rights Watch published a report on the **government support for older people in South Africa**. Over half of people over 75 years of age had a disability in 2016. The report found older people with disabilities are facing a range of barriers to living independently, including a lack of physically accessible housing and barriers to (affordable) support services. The report is also available in **Easy Read format**.

The World Federation of the Deafblind (WFDB) has launched a survey on the global situation of older persons with deafblindness. The purpose of this survey is to gather information for WFDB's First Global Report on older persons with deafblindness, which will be published by the end of 2023. This survey is for WFDB members, persons with deafblindness, organisations by and for persons with deafblindness as well as other organisations and professionals in the field of deafblindness. The survey will remain open until Sunday 6th August 2023 and can be accessed in English **here**.

Women and girls with disabilities

International Alert published a **report on the intersection of disabilities and violence against girls and women in sixteen districts of Tajikistan**. The report presents findings from 150 in-depth interviews and more than 2,000 survey responses from people with disabilities and parents of children with disabilities in 16 hard to reach districts in Tajikistan. The research found that 100% of women with disabilities interviewed had experienced sexual and gender-based violence and are rarely able to seek help due to social stigma. The report closes with recommendations for organisations and governments, including to address and mitigate systemic barriers for people with disabilities, recruiting women with disabilities to work in social protection institutions, and develop effective outreach mechanisms to reach people with disabilities and parents of children with disabilities.

Programme learning on engaging with OPDs

Sightsavers partnered with OPDs through the **Ghana Somubi Dwumadie programme**, a four-year disability programme in Ghana, with a specific focus on mental health. Sightsavers approached the Ghana Federation of Disability Organisations (GFDO) – the national umbrella organisation of OPDs in Ghana – and developed a technical assistance plan focusing on leadership strengthening, generating data for advocacy and monitoring and evaluation. By working with GFDO, and the GFDO gender committee, Sightsavers ensured that many groups of people with disabilities, especially minority groups that are often underrepresented – including people with albinism and people with psychosocial disabilities – could participate fully and directly benefit from the project. A key learning was that OPD partners need to be remunerated in a way that meets their needs and supports their growth, which may include in-kind and financial resources so that they have the time and capacity to fully engage. OPD partners led the process of engaging with decision-makers. This meant they could reach new contacts and networks, which they will still be able to access even now Sightsavers' contract on the project has come to an end. By collaborating with OPDs, the project will have a much more sustainable impact, as OPDs continue the work we started with them.

About the Disability Inclusion Helpdesk:

The Disability Inclusion Helpdesk provides research and technical assistance on disability inclusion to the UK Foreign, Commonwealth, and Development Office as part of the Disability Inclusive Development Programme. All our published reports are available on **our website**. Contact us via: **enquiries@disabilityinclusion.org.uk**