GLOBAL DISABILITY SUMMIT

Promoting Engagement of Organizations of Persons with Disabilities (OPDs) in Development and Humanitarian Action

Global Disability Summit (GDS) Discussion Paper, 2022

IDA International Disability Alliance

Norad

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→ Executive Summary

> *"The momentum that the international partners and global leaders have created on the inclusion of persons with disabilities has gained positive trends; however, a lot remains to be done. Please continue engaging persons with disabilities and their organisations in meaningful ways, the influence will eventually be felt by national and local governments and will lead to total inclusion of persons with disabilities in mainstream of community life."*
> **A respondent from an OPD in Uganda to IDA's second Global Survey on OPD participation, 2021**

This discussion paper was commissioned by the Norwegian Agency for Development Cooperation (NORAD) as a contribution to unpack, frame, guide and incentivize engagement of Organizations of Persons with Disabilities (OPDs) in development and humanitarian action through the Global Disability Summit (GDS) 2022. While disability inclusion is increasingly part of the global agenda, international cooperation policies and programs, efforts to enact commitments too rarely consider the perspectives of persons with disabilities themselves. This results in lack of relevance of interventions to the real concerns and priorities of persons with disabilities, missed opportunities or pervasive charity or medical approaches.

OPD engagement is therefore one of the overarching themes of the GDS 2022, in line with the motto of the disability rights movement 'Nothing about us without us', and with its legal translation into the general obligation of the Convention on the Rights of Persons with Disabilities (CRPD, Article 4.3) to actively involve persons with disabilities through their representative organizations.

The paper is intended to contribute towards the growing discourse on inclusive programming and meaningful engagement of persons with disabilities and their families through their representative organisation in development interventions.
It is hoped that the paper will be a resource for governments, donors, civil society organisations, and OPDs where relevant in their efforts towards inclusive and accessible development programmes.The International Disability Alliance (IDA) led the development of this paper in consultation with partners and allies, including the Global Action on Disability (GLAD) network and its members. The paper recalls the legal framework and rationale for the unique role of OPDs as representative organizations as envisaged in the CRPD (Part 1). It then takes stock of the current situation by exploring OPDs' perceptions of their participation in decision making and illustrating progress in promoting effective participation of OPDs as monitored by the UN system through the UN Disability Inclusion Strategy (Part 2). Using evidence from case studies collected through an open call, the paper attempts to unpack what OPD engagement means in practice, and to provide some evidence of what has worked
(Part 3). The paper concludes with recommendations for commitments and action through the GDS and beyond, to ensure that OPD engagement becomes a core component of disability-inclusive development and humanitarian action.

→ Glossary

ADD (International)	Action on Disability and Development
AHP	Australian Humanitarian Partnership
BWWDF	Cambodia's Battambang Women with Disabilities Forum
CA	Nepal's Constitutional Assembly
COAMEX	Mexico Coalition for the Rights of Persons with Disabilities
CRC	Convention on the Rights of the Child
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DFAT	Australian Department of Foreign Affairs and Trade
DPOD	Disabled People's Organisations Denmark
DRF	Disability Rights Fund
DSi	Down Syndrome International
FCDO	The United Kingdom's Foreign, Commonwealth and Development Office
FFO	Norwegian Federation of Organisations of Disabled People
GBV	Gender-based violence
GDS	Global Disability Summit
GLAD	Global Action on Disability Network
IADO	Iraqi Alliance of Disability Organisations
IASC	Inter-Agency Standing Committee Guidelines
ICCPR	International Covenant on Civil and Political Rights
IDA	International Disability Alliance
IDDC	International Disability and Development Consortium
IMHA	Indonesian Mental Health Association (Perhimpunan Jiwa Sehat)
INGO	International Non-Governmental Organisation(s)
IOM	International Organisation for Migration
IOSC	Rwanda's Isange One Stop Centre(s)
KDWCDO	Cambodia's Kampot Disabled Women and Children Disabled Organisation
KDWCDO	Cambodia's Khmer Disabled Women and Children Development Organisation
KSDWF	Cambodia's Kampong Speu Disabled Women Forum
NFDN	National Federation of the Disabled Nepal
NGO	Non-governmental Organisation(s)
NORAD	Norwegian Agency for Development Cooperation
OPD(s)	Organisation(s) of Persons with Disabilities
OPD EOs	OPD Engagement Officers
PADF	Pan American Development Foundation
PDF	Pacific Disability Forum
RIADIS	The Latin American Network of Non-Governmental Organisations of Persons With Disabilities and their Families
SDGs	Sustainable Development Goals
UDHR	Universal Declaration of Human Rights
UDPK	United Disabled Persons of Kenya
UN	United Nations
UNABU	Rwanda's Umuryango Nyarwanda w'Abagore Bafite Ubumuga
UNDIS	United Nations Disability Inclusion Strategy
UNDP	United Nations Development Programme
UNHCR	United Nations High Commissioner for Refugees
USAID	United States Agency for International Development
WCDFK	Cambodia's Women and Children Disability Forum Kampong Cham Province

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→ **Introduction**

Persons with disabilities constitute 15% of the world population. Yet, 1.2 billion people with disabilities continue to face barriers in their participation as equal members of society and are often excluded from decision-making processes on matters relating to or affecting their lives[1]. After decades of medical or charity approaches to disability, the Convention on the Rights of Persons with Disabilities (CRPD, adopted in 2006[2], and now one of the most embraced human rights instruments with 182 signatories to date[3]) brought about a radical shift in advancing the **recognition of persons with disabilities as equal subjects of human rights**. Its unique and transformative vision demands social change from societies to embrace diversity, rather than asking people to adjust and fit into a norm.

The CRPD emphasizes that all persons with disabilities have the right to fully and effectively participate and be included in society, and that conditions must be created to ensure their participation on an equal basis with others, including through equal recognition before the law and the power to make their own decision and choices[4].

The CRPD further recognizes the **role of organizations of persons with disabilities (OPDs)** as unique interlocutors and intermediaries to represent persons with disabilities in issues concerning them, and through its Article 4.3, places a general obligation to States to closely consult and actively involve OPDs[5]. This obligation equally applies across all areas covered by the Convention, including through international cooperation (Article 32) and in situations of risk and emergency (Article 11). OPDs are organizations "that are led, directed and governed by persons with disabilities and a clear majority of their membership should be recruited among persons with disabilities themselves"[6].

Following the adoption of the CRPD, several milestones have marked **progress towards the effective participation and inclusion of persons with disabilities**, including: references to persons with disabilities and clear commitments to 'leave no one behind' in the 2030 Agenda for Sustainable Development and indicator framework, inclusion of persons with disabilities in the Sendai Framework for Disaster Risk Reduction,

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1   Aguilar, Catalina Devandas (2016). *Report of the Special Rapporteur on the rights of persons with disabilities. United Nations Human Rights Council, A/HRC/31/62; International Disability Alliance (2020). Increasingly Consulted but not yet Participating: IDA Global Survey on Participation of Organisations of Persons with Disabilities in Development Programmes and Policies, 2020.* https://www.internationaldisabilityalliance.org/sites/default/files/ida_global_survey_complete_report_final.pdf

2   General Assembly (2007). *Convention on the Rights of Persons with Disabilities, A/RES/61/106.* https://www.un.org/development/desa/disabilities/resources/general-assembly/convention-on-the-rights-of-persons-with-disabilities-ares61106.html

3   For more information on ratification, see: https://www.ohchr.org/Documents/HRBodies/CRPD/OHCHR_Map_CRPD.pdf

4   Quinn, Gerard (2021). *Report of the Special Rapporteur on the rights of persons with disabilities. United Nations Human Rights Council, A/76/146*

5   Comment No, G. 7 (2018) *on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention. Adopted on 9 November 2018. UN Doc CRPD. C/GC/7. [hereinafter General Comment No.7 (2018)], para 42-48.*

6   *Report of the Special Rapporteur on the rights of persons with disabilities. United Nations Human Rights Council, A/HRC/31/62, Para 16-17; see also General Comment No.7 (2018), para 11.*

the adoption of the Inter-Agency Standing Committee Guidelines (IASC) Guidelines on Inclusion of persons with disabilities in humanitarian action, a landmark UN Security Council resolution on inclusion of persons with disabilities in responses to armed conflict, or the 968 commitments made at the 1st Global Disability Summit in 2018.

While progress is significant, it takes a lot more effort to turn these promises into action, and **initiatives often fail to engage and consult with persons with disabilities themselves**. Reasons vary but usually relate to gaps in understanding disability from a rights-based perspective or prejudice regarding OPDs' capacity to contribute, limited knowledge of and contacts with OPDs, gaps in ensuring inclusive and accessible venues, information and methods to support active engagement of OPDs. This significantly reduces the relevance and impact of disability-inclusive investments and perpetuates paternalistic approaches whereby persons with disabilities are only recipients of aid. The Covid-19 global pandemic brutally recalled and exposed pervasive discriminations, with dramatic consequences as lives of persons with disabilities are not considered of equal importance.

Against this background, the Global Disability Summit 2022 has set OPD engagement as one of the overarching themes for the GDS. By doing so, the three co-hosts – the Government of Norway, the Government of Ghana and the International Disability Alliance – wish to recall the **importance of rights-based approaches to disability-inclusive development and humanitarian action, which require more systematic and meaningful engagement with representative organizations of persons with disabilities** and paying particular attention to underrepresented and most marginalised groups.

This discussion paper aims to **unpack, frame, guide and incentivize greater and more meaningful OPD engagement**. While OPD engagement is an essential component of disability-inclusive development and humanitarian action in line with the CRPD, other sources of evidence also inform quality, including collecting disability-disaggregated data, research and learning, or mechanisms for feedback from persons with disabilities and their families.

This discussion paper recalls the legal framework and rationale for the unique role of OPDs as representative organisations as envisaged in the CRPD (part 1). It then takes stock of the current situation by exploring OPDs' perceptions of their participation in decision making, and illustrating progress in promoting effective participation of OPDs as monitored by the UN system through the UN Disability Inclusion Strategy (part 2). Using evidence from case studies collected through an open call, the paper attempts to unpack what OPD engagement means in practice, and to provide some evidence of what has worked (part 3). Finally, the paper concludes with recommendations for commitments and action through the GDS and beyond, to ensure that OPD engagement becomes a core component of disability-inclusive development and humanitarian action (part 4).

More information on the methodology followed to develop this discussion paper is available in Annex A.

1 Part 1

Why it matters: legal framework and rationale for engagement of Organizations of Persons with Disabilities in development and humanitarian action

Participation as a human right

Participation is a core human rights principle, firmly rooted in international human rights law. The Universal Declaration of Human Rights (UDHR) states that "every person has the right to take part in the government of his or her country, directly or through chosen representatives, and the right to equal access to public service"[7].

With the CRPD, participation takes a new scope and purport, as both a process and an outcome. The full and effective participation of persons with disabilities in society on an equal basis with others is recalled in the purpose of the Convention (Article 1), as a general principle (Article 3), as a general obligation (Article 4,3), and a cross-cutting issue under specific rights, such as the right to participate in political and public life. Unlike other human rights instruments, the CRPD enshrines participation as a general obligation for States:

> *"In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations."*
> **CRPD Article 4.3**

Participation as a process supports the realization of the full and effective participation and inclusion in society as a desired outcome. The CRPD hence envisages participation

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7   The principle of participation through the right to equal participation in public affairs, the right to vote and to be elected, and the right to have equal access to public service are reaffirmed in the International Covenant on Civil and Political Rights (ICCPR Article 25). Article 7 of the Convention on Elimination of Discrimination Against Women (CEDAW) obligates States to "ensure to women the right to vote and be elected, and to participate in the formulation of government policy and the implementation, and to hold public office, and to participate in non-governmental organizations and associations concerned with public life." The Convention on the Rights of the Child (the CRC) obligates states to ensure to children with disabilities to freely express their views and actively participate in the community (CRC Article 12 and 23.1).

of persons with disabilities and their representative organization in development and implementation of legislation and policies, in the monitoring of the CRPD[8], through international cooperation[9] and in the composition of the Committee on the Rights of Persons with Disabilities[10].

The nature of engagement is further qualified through numerous references of **"full and effective" participation** and mentions specifically "partnerships" in context of international cooperation. With these qualifiers, the CRPD adds another layer of obligation to States that participation is not just about a right but that certain parameters must be met to ensure that persons with disabilities and their representative organizations are meaningfully and actively engaged.

Participation through OPDs

The CRPD stresses the importance of organisations *of* persons with disabilities (OPDs) as representative organisations. OPDs are a specific type of civil society organization and should be distinguished from others, such as organisation *for* persons with disabilities. OPDs are those organisations that are led, directed and governed by persons with disabilities[11], and bring a unique perspective to speak on their own behalf. Organisations of families of persons with disabilities are also considered OPDs (General Comment 7, para 12 d). The CRPD clearly establishes OPDs as intermediary bodies between policy makers and persons with disabilities[12]. As such, OPDs actually play diverse roles as civil society organisations, from voicing the concerns of persons with disabilities, to providing peer support, facilitating access to information and services (sometimes even delivering services), providing technical guidance on disability or acting as 'watchdogs' on the rights of persons with disabilities.

As such, OPDs are a key component of a diverse civil society and an important contributor to democracy. CRPD General Comment 7 provides a roadmap for State's legal obligations and includes recommendations and guidance on how to effectively ensure the participation of OPDs in the implementation and monitoring of the CRPD. It also clarifies the duties of governments in supporting OPDs to freely register as civil society organisations, and in ensuring they can access resources including funding and capacity building, while maintaining their independence from the State. The important role of OPDs as representative organisations and intermediary bodies also carries with it a responsibility to provide quality representation. This includes the capacity to represent the diversity of persons with disabilities, to build a cohesive collective action - both within the disability movement and with other allies - to articulate demands strategically, and to maintain independence.

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8   General Assembly (2007). Convention on the Rights of Persons with Disabilities, A/RES/61/106, Article 33

9   General Assembly (2007). Convention on the Rights of Persons with Disabilities, A/RES/61/106. Article 32

10   General Assembly (2007). Convention on the Rights of Persons with Disabilities, A/RES/61/106. Article 34 (3).

11   General Comment No.7 (2018), para. 11, page 4

12   Cote, A (2020). The unsteady path: Towards meaningful participation of Organizations of Persons with Disabilities in the implementation of the CRPD and SDGs.
     https://bridgingthegap-project.eu/wp-content/uploads/The-unsteady-path.-A-pilot-study-by-BtG.pdf

While acknowledging this responsibility, the burden of proof should not be reversed: **participation as a right should be ensured in ways that seek to consolidate, rather than challenge, the roles and leadership of OPDs**. Setting unfair expectations or conditions to OPD participation, failing to remove barriers to participation, for example by not changing complex mechanisms or inaccessible venues, results in discrimination[13]. Part 3 of this paper presents examples of strategies to invest in and build capacities of OPDs as one of the preconditions for inclusive development.

The added value of OPD engagement

Participation has been one of the key features of a rights-based approach. OPD participation is not merely a moral imperative but as it brings multiple benefits for relevance, quality, impact and sustainability of development and humanitarian work: this includes promoting ownership, accountability, better outcomes, as well as agency and empowerment for OPDs to be long-term and efficient contributors. "Done well, DPO engagement can provide mutual benefit, with development programs improving their reach and effectiveness, and DPOs expanding their voice, gaining influence and receiving resources. Done poorly, DPO engagement risks diverting DPOs from their own priorities, overwhelming their capacity and available resources, and perpetuating the marginalisation already experienced by many people with disabilities.[14]"

OPD engagement promotes ownership

The effective and meaningful participation of organizations of persons with disabilities and their families in development and humanitarian action can promote a sense of ownership. As intermediaries, organizations of persons with disabilities can act as a force multiplier given their geographical, demographic and diversity in composition of their membership. By reaching out to their membership at regional, national and local level, and engaging them in topical issues, OPDs can create a common understanding and endorsement of views such as call for action which promotes a sense of ownership, acceptability and legitimacy among their members.

OPD engagement promotes accountability

OPD engagement promotes accountability internally and externally. Internally, the recruitment of OPD members is defined by common goals that are defined and agreed upon by members. As such these rules assist in defining the priorities of persons with disabilities, related advocacy strategies and in accounting to their members for progress. Externally, OPDs act as a watchdog and as part of civil society have a responsibility to monitor governments compliance with the fundamental human rights standards (Article 33.3). OPDs can identify areas that the States lag and engage the State to ensure accelerated implementation of disability inclusive programmes.

13　General Assembly (2007). *Convention on the Rights of Persons with Disabilities, A/RES/61/106*

14　Australian Aid, Creating a business as usual, Jan 2018

OPD engagement contributes to better outcomes

The effective and meaningful participation of organizations of persons with disabilities in development and humanitarian action can result in better outcomes[15]. Organizations of persons with disabilities and their families, just like persons with disabilities, are diverse. This diversity, if effectively promoted, ensures that through consultations processes at local, national, regional and global levels, OPDs collect and channel diverse views of their members, thereby enhancing the chances that policies and programs are informed by and relevant to the priorities of this diversity. As evident from the drafting of the CRPD, close consultation and active involvement of persons with disabilities, through organizations of persons with disabilities and their partners, had a positive impact on the quality of the final text of the CRPD and its relevance for persons with disabilities[16].

> *"When persons with disabilities participate in decision-making processes, it provides strong support towards ensuring that policies, strategies, programmes and operations to be more effective in addressing barriers to inclusion and more relevant in supporting their full and equal participation. Persons with disabilities have first-hand experience of the challenges they face and know better what can be done to enhance their rights and wellbeing. In addition, active participation of persons with disabilities and their representative organizations is a key part of shifting attitudes and dismantling stigma".*
> **UN Disability Inclusion Strategy**
> Guidelines on consulting with persons with disabilities

OPD engagement promotes agency and empowerment

The active engagement of persons with disabilities through their representative organizations is also a reaffirmation of persons with disabilities personhood, ability to contribute and shape their decisions[17]. Partnership is about meaningful dialogue, co-production and willingness to engage OPDs as trusted stakeholders and counterparts. Through participation, OPD representatives get involved in public decisions, acquire information about how policy making works, how they can contribute to it, and enhance their advocacy, networking and negotiation skills. This may lead to better advocacy outputs, identification of allies for coalitions, greater recognition of OPD contributions and further opportunities to participate[18].

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15   Aguilar, Catalina Devandas (2016). *Report of the Special Rapporteur on the rights of persons with disabilities. United Nations Human Rights Council, A/HRC/31/62*

16   General Comment No. 7, 2018, para 1; See also the proceeding of the Ad Hoc Committee available at: https://www.un.org/esa/socdev/enable/rights/a_58_118_e.htm

17   General Comment No.7, Para 21

18   General Comment No.7, Para 21

2 Part 2

What it means in practice: unpacking meaningful participation and understanding the current situation

Principles underpinning meaningful participation of OPDs

There is no commonly acknowledged definition of meaningful participation of organizations of persons with disabilities (OPDs). In the context of the CRPD, participation is both an outcome, demonstrating the realization of human rights of persons with disabilities in all areas of life, and a process, with active engagement, consultation and involvement as a direct contribution to achieve this outcome. This discussion paper focuses on OPD engagement and participation as a process and condition to ensure participation as an outcome.

The **Committee on the Rights of Persons with Disabilities in General Comment No.7** sets a number of obligations to States to guarantee effective and meaningful participation of persons with disabilities through organization of persons with disabilities. These sets of obligations can also be interpreted as pre-conditions for meaningful participation.[19]

They include:

- Transparency of consultation processes;

- Accessibility to all facilities and procedures related to public decision-making and consultation;

- Provision of reasonable accommodation including meeting assistants, support persons, information in accessible;

- Allocation of funds for disability related costs to OPDs to attend meetings and technical briefings;

- Consultation based on transparency, mutual respect and meaningful dialogue set with reasonable and realistic timelines;

- Reflection of OPDs recommendations in final documents and communication of outcome of the process to OPDs;

- Formalized consultation procedures;

- Legal recognition of participation as right;

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19   General Comment No. 7, 2018, para 42-66.

- Funding of OPDs to facilitate their functioning and existence;

- Consultations of OPDs that represent persons with disabilities in all their diversities including but not limited to women, older persons, children, those requiring high levels of support, victims of landmines, migrants, refugees, asylum seekers, internally displaced persons, undocumented and stateless persons, persons with actual or perceived psychosocial impairments, persons with intellectual disabilities, neurodiverse persons, including those with autism or dementia, persons with albinism, permanent physical impairments, chronic pain, leprosy and visual impairments and persons who are deaf, deafblind or otherwise hearing-impaired and/or those living with HIV/AIDS;

- Empowerment of OPDs to participate in public affairs including development of technical, administrative and communication skills;

- Periodic review of existing participation and consultation mechanisms.

Drawing from a global survey on OPDs' perceptions of their participation, the International Disability Alliance (IDA) attempted to define meaningful participation:

> *"Meaningful participation that respects, values and considers the unique role and perspective of OPDs as organizations representing the diversity of persons with disabilities, and enables their regular and effective engagement, by ensuring equal opportunities to contribute to decision-making. (…) Meaningful participation as expected from OPDs is participation that seeks the highest levels of shared decision-making on all issues that concerns persons with disabilities, whether for domestic issues, through international cooperation or in situations of risk and humanitarian emergencies."* [20]

As per the UNDIS, meaningful participation is also about:

> *"Recognizing that engaging with persons with disabilities and their organizations is a two-way exchange, not just telling them what is being done. It means there is genuine interest in listening to OPDs' contributions, discussing their priorities and concerns, and being willing to act upon them. It is about building a dynamic relationship based on partnership and not considering consultation as a one-off event."* [21]

Meaningful engagement is not just an outcome in itself, but also a process. The enabling mechanisms such as accessibility, reasonable accommodation, etc. that are both essential and necessary to make people with disabilities and their families feel valued and empowered form a critical component of how we define meaningful participation.

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[20] International Disability Alliance (2020). *Increasingly Consulted but not yet Participating: IDA Global Survey on Participation of Organisations of Persons with Disabilities in Development Programmes and Policies, 2020.* https://www.internationaldisabilityalliance.org/sites/default/files/ida_global_survey_complete_report_final.pdf page 9.

[21] United Nations Disability Inclusion Strategy, 'Guidelines, Consulting Persons with Disabilities', (May 2021), page 17.

OPDs' perceptions of their participation: learning from the 1st and 2nd IDA Global Survey on OPD participation[22], from OPDs' engagement in partnerships and Covid-19 impact on OPDs

To collect broader evidence and analyze the reality of OPD's engagement in decision-making, the IDA Global Survey was developed in 2019. It is part of a strategy for holding decision makers on local, national, and regional level accountable for their commitments under Articles 4.3[23] and 33.3[24] of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and General Comment No. 7. Overall, the Global Survey takes stock of participation of OPDs in programmes, and policies of local, national, regional, and international decision makers by assessing the OPD´s perceptions of the quality, depth, scope, and relevance of their own participation with governments, funding agencies and the UN. As it is meant to become a tool to measure change of the perception of OPDs regularly, the survey has been conducted twice already (in 2019 and 2021).

The main message of the report is that **while OPDs are more consulted than before, levels of participation remain insufficient**. Where participation is ensured, it is experienced by many OPDs as a challenging process, hampered - among others - by a lack of accessibility and reasonable accommodation and a lack of consideration for the views expressed by OPDs. Actually, consultations and involvement often result in tokenistic participation. For organizations usually excluded from decision-making, these barriers can act as deterrents to further engagement.

The IDA Global Survey provides unprecedented information on OPDs' perceptions of their role, influence, and experience of participation. The findings below also come from additional experience and evidence gathered from IDA and IDA members' engagement in partnerships (for example consortium projects such as Inclusive Futures), and a study carried out by FCDO to understand and analyze the impact of Covid-19 on OPDs in Nigeria, Bangladesh, and Zimbabwe[25].

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22 Findings from the 1st IDA Global Survey can be found in the full report here:
https://www.internationaldisabilityalliance.org/sites/default/files/ida_global_survey_complete_report_final.pdf
Findings of the 2nd IDA Global Survey are preliminary at this stage, as the 2nd report will be released in 2022.

23 *"In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations."*

24 *"[....] Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process."*

25 Inclusive Futures (2021) *Consequences of Exclusion: A Situation Report on Organizations of People with Disabilities and COVID-19 in Bangladesh, Nigeria, and Zimbabwe.*
https://www.sddirect.org.uk/media/2268/english-situation-report-opds-covid-19-report-final.pdf

Who? Groups that are invited to participate

Participation of persons with disabilities is not equal across the diverse constituencies of the disability rights movement. The Global Survey shows that persons with psychosocial disabilities, persons with intellectual disabilities, persons with deafblindness, deaf persons, women with disabilities, and indigenous persons with disabilities are still largely left out of consultation and decision-making processes.

On what? Issues on which OPDs are invited to participate

OPDs are not consulted on all issues that concern them. As shown by the 1st Global Survey report (2019), OPDs are primarily consulted on disability-specific issues, such as disability policies. The preliminary findings of the 2nd IDA Global Survey (2021), however, suggest that consultation is expanding beyond this scope: about half or more of OPD respondents report that they are consulted on disability-specific AND other issues such as education, culture etc (with slight variations across different types of decision makers with whom they engage). International cooperation partners (including the UN and donors) still involve OPDs slightly more on disability-specific issues, while governments increasingly engage with them also on other issues.

Barriers to OPD participation

The 2nd Global Survey shows that about 32% of OPDs report that they are satisfied with the work with their local or national governments, with whom OPDs tend to engage a lot. OPD satisfaction is much higher (55%) about their engagement with the UN, although they do engage much less. Overall, OPDs identify a range of barriers that prevent and hamper their meaningful participation in decision-making processes:

- **Financial barriers:** Lack of financial resources and capacity of OPDs is identified as a major barrier as organizations struggle to exist and operate. OPDs face strong opportunity costs as they get solicited to engage in a growing number of issues, with a risk of being pushed to engage in issues that are funded for rather than their priority issues[26]. While 40% of respondents to the 2nd IDA Global Survey reported that their funding increased (as compared to 32% in the 1st Global Survey in 2019), about 30% still report decreasing of their funding, which undermines those OPDs independence and autonomy as well as their ability to develop their capacities and engage with others. On the contrary, evidence suggests that flexibility in funding (especially in times of crisis such as during the Covid-19 pandemic) and adaptation of conditionality for funding can make a huge difference in OPDs' ability to engage.

- **Physical and communication barriers:** Gaps in ensuring accessibility and reasonable accommodation prevent OPDs from accessing venues and information shared prior, during and after consultations or project events.

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26 OPDs may face severe opportunity costs in choosing to engage with multiple development agencies at the expenses of sustained and deeper engagement with central and local authorities.
Cote, A (2020). *The unsteady path: Towards meaningful participation of Organizations of Persons with Disabilities in the implementation of the CRPD and SDGs.*
https://bridgingthegap-project.eu/wp-content/uploads/The-unsteady-path.-A-pilot-study-by-BtG.pdf

This includes realistic budgeting for accessibility and reasonable accommodation, such as Sign Language interpretation or supporting accessible transportation to workshop venues, or people being denied access to good support, among others, but also adequate timeframes for preparation, which is particularly critical for underrepresented groups, such as persons with intellectual disabilities or persons with deafblindness, to get familiar with content and process. Although OPD representatives might make it to the venue, lack of accessibility and reasonable accommodation de facto nullifies their participation. This has worsened following the Covid-19 pandemic as work shifted online revealing a disconcerting digital divide.

- **Attitudinal barriers:** Poor attitudes and a lack of knowledge about how to engage with persons with disabilities result in negative environments and fewer opportunities for OPDs to take part. For example, it is not uncommon that persons with intellectual disabilities are not consulted because of pervasive stigma and assumptions that they cannot contribute. Unequal attention to engaging with underrepresented groups (including persons with psychosocial disabilities, persons with intellectual disabilities, persons with deafblindness, deaf persons, women with disabilities, and indigenous persons with disabilities) can perpetuate their exclusion. When they do get involved, many OPDs report that their views are rarely considered, which can be a deterrent to further engagement.

- **Lack of understanding of the nature of OPDs:** Gaps in the understanding of the political nature of OPDs as representative organizations can frequently lead to a few individuals with disabilities being 'hand-picked' for consultations regardless of their role and mandate in the disability rights movement. This not only does not lead to meaningful representation, but can challenge or weaken the disability rights movement, instead of working with leaders who have a mandate and supporting greater representation of most marginalized groups where it does not exist. In some cases, power dynamics are also at play, as making space and way for OPDs to contribute may lead to different project orientations and ways of working, which not all decision-makers are equally ready to change.

Challenges to participation from the wider environment

The above-mentioned barriers occur in wider political and socioeconomic contexts influencing positively or negatively the participation of civil society in general. For example, the level of buy-in within various levels of government may vary, or processes may be too lengthy or complex for OPDs to engage or feel they make a difference through their participation. States retain the ability to facilitate or constrain participation through administrative procedures and by limiting access to international funding. This is further compounded by the increasingly shrinking civic spaces in which OPDs operate.[27] In addition, there is also a growing recognition of the political nature of public participation itself, which if not supported through preconditions can be used to legitimize policies and processes that preserve status quo or perpetuate inequalities.[28] This is particularly relevant for under-represented groups that may not have the capacity to organise and engage or that may be marginalised within the disability movement.

OPDs are equally affected by contextual factors that may foster or hinder civil society participation. However, in times of crisis, OPDs may be more affected than other civil society groups. Indeed, as reviewed by FCDO and partners through a study on impact of the COVID-19 pandemic on OPDs[29]: "instead of being invited to work with governments and humanitarian actors in disaster and response planning, many OPDs found themselves trying to mitigate the consequences of policy decisions that had not adequately considered people with disabilities". As stigma and power asymmetry have historically kept OPDs away from decision-making, a risk remains that INGOs (sometimes with good intention) speak on behalf of OPDs instead of fostering more collaborative processes[30].

27   Cote, A (2020). The unsteady path: Towards meaningful participation of Organizations of Persons with Disabilities in the implementation of the CRPD and SDGs.
https://bridgingthegap-project.eu/wp-content/uploads/The-unsteady-path.-A-pilot-study-by-BtG.pdf

28   Cote, A (2020). The unsteady path: Towards meaningful participation of Organizations of Persons with Disabilities in the implementation of the CRPD and SDGs.
https://bridgingthegap-project.eu/wp-content/uploads/The-unsteady-path.-A-pilot-study-by-BtG.pdf

29   Inclusive Futures (2021) Consequences of Exclusion: A Situation Report on Organizations of People with Disabilities and COVID-19 in Bangladesh, Nigeria, and Zimbabwe.
https://www.sddirect.org.uk/media/2268/english-situation-report-opds-covid-19-report-final.pdf
page 14

30   Inclusive Futures (2021) Consequences of Exclusion: A Situation Report on Organizations of People with Disabilities and COVID-19 in Bangladesh, Nigeria, and Zimbabwe.
https://www.sddirect.org.uk/media/2268/english-situation-report-opds-covid-19-report-final.pdf
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3 Part 3

Meaningful OPD engagement in practice: case studies

Unpacking key components of meaningful participation

In the context of this discussion paper, meaningful engagement/ participation of OPDs is approached from two perspectives, as equally necessary for a rights-based approach to inclusive development and humanitarian action: (1) Enabling participation by creating preconditions for meaningful participation at OPD level; and (2) Realizing participation in practice as a two-way collaboration. This section explores through a variety of concrete examples what can work to foster meaningful OPD engagement[31]. The case studies demonstrate ways to operationalise meaningful OPD engagement, an area of work that is still evolving. Moving forward, more and more such evidence and learning would require to be generated that can continually inform disability inclusive development in practice.

Case studies on creating preconditions for meaningful participation at OPD level

Preconditions necessary to ensure that OPDs can develop skills, capacities and access resources that build their profile as relevant contributors to development and humanitarian policies and programs. Like any other discriminated group, OPDs have not had equal access opportunities to engage and acquire resources (including funding, organizational agency, technical knowledge, and skills) to be considered meaningful contributors. This is even more the case for underrepresented groups of persons with disabilities, such as persons with deafblindness, persons with intellectual disabilities, persons with psychosocial disabilities and persons with disabilities facing intersecting forms of discrimination such as women with disabilities, youth with disabilities, indigenous people with disabilities, or persons with disabilities with diverse Sexual Orientation, Gender Identity, Expression and Sex Characteristics (SOGIESC). Dedicated support is needed to break this negative circle and develop capacities for OPDs to engage. This part recognizes the need to invest in OPDs to develop as policy entrepreneurs and advocates who can be key counterparts to decision makers.

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31 Case studies often address simultaneously several aspects of OPD engagement but have been 'assigned' to a particular component that was perceived as particularly illustrative of one of the 6 dimensions covered by the call for case studies.

Organisational development

The capacity and strengths of OPDs as representatives of very marginalized population groups greatly vary. In many cases, OPDs are not legally registered, especially OPDs of underrepresented groups of persons with disabilities, and are often expected to contribute on a voluntary basis. Investing in OPDs and strengthening their organisational capacities is therefore a prerequisite to support meaningful participation. There are various aspects of organizational development. These can range from opportunities and resources that allow OPDs to develop their organizational capacity, including leadership development particularly for marginalized and underrepresented groups, governance, project management, monitoring and evaluation, financial management and fundraising; to enabling their access to and usage of accessible digital technologies. At the same time a self-identified capacity gaps and needs assessments by OPDs is important to ensure ownership of the process and to ensure it is inclusive and bottom-up[32].

It is also important to note that capacity building programs need to consider the varying contexts and unique realities of different OPDs and not one approach may work for all. The case study from Cambodia demonstrates how an intervention by ADD in organisational capacity building was able to support OPDs to lead the discourse on combating high levels of violence faced by women with disabilities.

**Key lesson 1:
Organisational capacity development supports OPD leadership and capacity to forge partnerships**

Supporting Cambodian women with disabilities to lead the way in combating the high levels of violence they face – a case study by ADD International.

Women and girls with disabilities face high levels of violence, rooted in high levels of violence and exclusion from services lie in discriminatory attitudes and social norms related to gender and disability. Women continue to be an underrepresented group within the disability rights movement, particularly in leadership roles within OPDs. ADD's intervention[33] focused on ensuring that women with disabilities' lived experiences and active engagement remain at the heart of both prevention and service response strategies and action in Cambodia.

The practice was implemented in cooperation with five women-led OPDs (Battambang Women with Disabilities Forum – BWWDF, Kampong Speu Disabled Women Forum – KSDWF, Women and Children Disability Forum Kampong Cham Province – WCDFK, Kampot Disabled Women and Children Disabled Organisation - KDWCDO, Khmer Disabled Women and Children Development Organization - KDWCDO and two local non-governmental organisations in eight communes in six districts in five provinces of Battambang, Kampong Speu, Kampot, Svay Rieng and Tbong Khmum from 2018 to 2021.

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32   GDS 10 commitments

33   Funded by the United Nations Trust Fund to End Violence Against Women (UN Trust Fund or UNTF)

Intervention

This intervention supported them to combat the high levels of violence they experience by engaging effectively with key targets using a two-fold approach:

1. **Leadership and organisational capacity:** supporting the development of OPDs by strengthening women's membership, voice, and leadership in OPDs, building technical skills in gender-based violence (GBV), prevention and responses, and strengthening organisational capacity in advocacy and governance driven by a recurring supported cycle of OPD self-assessment, planning, implementation, review and re-planning. The practice facilitated the development of community-level OPDs where women with disabilities were supported to form self-help groups (SHGs), to join existing OPDs, or to create new ones, including women-led OPDs. ADD's support consisted of investing in building the organisational strength, through an initial development plan co-developed by the OPD with ADD. As the process is repeated over time, OPDs have said they became more confident as they saw progress and understood the significance of their roles in society. The scores of all four women led OPDs increased to good or high capacity across the four gender capacity areas (policy, knowledge, and skills, conscious, programme) compared to the baseline scores of low and average capacities.

2. **Networking and partnerships:** building bridges by making introductions and convening spaces to build engagement and new partnerships for the group. For example, OPDs were connected with local government and service providers and both parties are supported to work together. OPDs receive assistance from local authorities to address violence, which in turn makes local authorities more likely to include disability in their work. At the national and provincial levels, OPD members are supported to engage with the government's GBV Working Groups.

Outcomes

In this practice, investing in organizational development not only led to leadership development of the group, but also allowed women and girls with disabilities experiencing violence to shift community level narratives around violence. Women with disabilities developed their own unique voice, engage with community and local government leaders, and build strong relationships with local governments and service providers leading to an overall improvement in disability inclusion in mainstream GBV prevention and response systems.

As a result of this practice, women and girls provide direct peer support to other women and girls with disabilities experiencing violence by helping them to report incidents, access health and social services, seek justice and prevent recurrence by engaging with families and perpetrators.

Technical capacity building

This section looks at what works to equip OPD activists with the technical skills, knowledge, and capacities that they need to meaningfully engage as development/ humanitarian partners and/or policy entrepreneurs shaping more inclusive societies. As more and more demands are made from OPDs to provide technical inputs to human rights, development, and humanitarian work, it is important that OPD leaders and members equip themselves with the skills to respond to such requests. In addition, enhanced technical skills within the disability rights movement facilitates greater uptake of OPDs' priority issues and sustainability of programme interventions. Two case studies outlined below speak to how technical capacity building of OPDs support their meaningful participation in policies and programmes.

Key lesson 2:
Technical capacity development of OPDs leads to mutual benefits and reinforcement of both OPDs and partners towards better impact

Supporting people with disabilities in the Pacific to shape the agenda for inclusive disaster risk reduction and humanitarian response – a case study by the Australian Department of Foreign Affairs and Trade (DFAT)

People with disabilities are disproportionately affected in disasters and humanitarian crises. As recognised by Article 11 of the CRPD and the Sendai Framework, disaster risk reduction, preparedness and humanitarian action must be disability inclusive. Unfortunately, OPDs often lack the human resources, expertise, core organizational funding and networks to be able to engage in disaster management planning. Many OPDs in the Pacific have only one or two paid staff members and rely on volunteers. Humanitarian agencies in the Pacific needed to find ways to engage with regional and national disability movements in a way that does not overwhelm OPDs but would build core capacities and contributes to the disability movement's own priorities and objectives.

The Australian Government's Department of Foreign Affairs and Trade (DFAT), funds the Australian Humanitarian Partnership (AHP) Disaster READY program, which is an AUD 50 million disaster preparedness and resilience program implemented by Australian NGOs and their local networks across five countries around the Pacific[34] : Fiji, Papua New Guinea, Solomon Islands, Vanuatu, and Timor-Leste. Recognising that people with disabilities cannot be left out of disaster preparedness, the program directed resources to Pacific OPDs, to ensure they are resourced and empowered to share their lived experience and expertise with the implementing partners to make the program more inclusive.

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34   For more information on the programme: https://www.australianhumanitarianpartnership.org/about

This case study highlights the significant role a bilateral donor can play to mandate that appropriate resources flow to OPDs to ensure their technical capacity building, meaningful participation in disaster preparedness, and response programming.

Intervention

To address the above-mentioned challenges, DFAT dedicated program resources for Pacific OPDs to ensure they are empowered to share their lived experience and expertise with implementing partners. This includes program funding by mainstream Australian Humanitarian Partnership (AHP) agencies to cover one full-time staff position dedicated to disability-inclusive humanitarian action in each national OPD in the five countries where the Disaster READY is implemented. The AHP agencies can therefore tap into their expertise in disability inclusion, as well as learn from the lived experiences and perspectives of people with disabilities.

This is complemented by technical capacity to national OPDs through training and direct engagement of OPDs with humanitarian agencies in-country, with advisory support from the Pacific Disability Forum (PDF) and CBM Global Inclusion Advisory Group, who also facilitate cross-country learning.

Outcomes

Through this practice, OPDs gain direct access to humanitarian sectoral knowledge, gain a meaningful seat at the table, and are able to influence the disaster preparedness projects of NGOs. OPDs built technical capacity in DRR and developed mutually beneficial partnerships with humanitarian partners.
A particular interesting aspect of this practice is the bi-directional learning positioning OPDs as contributors and not only recipients: OPDs strengthened the capacity of NGOs to implement in a disability-inclusive way (through dedicated OPD positions resourced by the project), while NGOs provided organisational strengthening support to OPDs so they can more confidently engage as technical advisors.

Key lesson 3:
Technical capacity development is a process that requires sustained investment and leads to greater recognition of OPDs' added value to development

Building capacities at intersections and margins: supporting women with disabilities to ensure inclusive responses to GBV in Rwanda – A case study by the Disability Rights Fund (DRF)

Although progress has been made towards gender equality in Rwanda, women and girls with disabilities still face considerable stigma and exclusion, disproportionately higher rates of gender-based violence (GBV), and barriers when accessing justice and services for survivors. To address this, the Disability Rights Fund (DRF) has been providing grants and technical assistance since 2015 to Umuryango Nyarwanda w'Abagore Bafite Ubumuga (UNABU), an organization of women with disabilities.

This support has helped building the technical capacity of UNABU to effectively advocate for inclusive and accessible GBV prevention and response efforts in Rwanda, especially critical during the pandemic.

Intervention

In 2018, UNABU received DRF funding and technical assistance for research which found that more than 40% of Rwandan women and girls with disabilities surveyed had experienced some form of violence and yet could not access services for survivors at the government's Isange One Stop Centres (IOSCs).

With DRF support prior to the Global Disability Summit of 2018, UNABU and other local OPDs engaged with the Rwandan government to develop their GDS18 commitments. This led to the government making a commitment to ensure IOSCs are accessible to people with disabilities. To follow up on this commitment, UNABU used DRF coalition funding to develop an alliance with Haguruka (a national women's rights NGO that addresses GBV through legal assistance, psychosocial support, and referrals for survivors) and Legal Aid Forum (a network of NGOs, educational institutions, and law clinics that provides free services to marginalized groups).

This Coalition built a team of community mobilizers - themselves women with disabilities and survivors of violence – and trained them on identifying cases of GBV, facilitating referrals to IOSCs and other community services, and helping survivors navigate the justice system to seek redress and support. In addition, UNABU developed an accessibility checklist to encourage IOSC self-assessment, and organized reflection meetings with IOSC staff on post-assessment actions. The Coalition held workshops for IOSCs with other GBV and justice stakeholders to encourage collaboration.

UNABU followed up with site visits to address challenges and recommend reasonable accommodations needed to effectively support women and girls with disabilities.

The Coalition has also been working to mainstream gender and disability in existing frameworks – including Rwanda's Legal Aid Policy, Penal Code, and Strategic Plan -by leading reviews and engaging with relevant stakeholders to address gaps. Over the pandemic period, ongoing financial and technical support from DRF to implement COVID-safe and responsive advocacy facilitated further expansion of the Coalition's work.

Outcomes

The Coalition has conducted accessibility audits in 39 IOSCs throughout Rwanda and recently disseminated the findings through a national dialogue. Actionable recommendations based on those findings are being developed through a peer-to-peer technical assistance provided by a DRF grantee in Uganda with extensive accessibility expertise. The Coalition has also sensitized nearly 400 stakeholders on violence against women and girls with disabilities, trained 35 mobilizers on the use of smartphones for reporting GBV (including data security), and provided to 879 girls and women with disabilities in UNABU's village self-advocacy groups. Initial data indicates that these efforts have led to substantially increased access to services for survivors, including 40 case referrals involving women and girls with disabilities.

Over the past seven years of consistent financial and technical support, UNABU's staff developed the knowledge, skills, reach, and network to foster lasting change and now supports 8,000 women and girls with disabilities across Rwanda. Trainings during DRF grantee convenings – coupled with targeted technical assistance to build knowledge and skills specific to gender-disability intersectionality – have positioned UNABU as a subject matter expert respected by officials, OPDs, and mainstream civil society actors alike. Whether being honoured by the US Embassy in Rwanda or serving as co-chair of a Disability Coordination Forum sub-committee, UNABU's staff led by women with disabilities has leveraged this expert standing to promote their rights through mechanisms ranging from GDS commitments to COVID-19 committees.

Movement building

Promoting OPD engagement in ways that consolidate the movement as a whole requires explicit attention. This section looks at what works to support greater coordination across different constituencies of the disability rights movement, to promote a greater participation and voice of underrepresented groups of persons with disabilities, create synergies across groups and to build cohesion and solidarity across different levels of the disability rights movement.

The Bridge CRPD-SDGs training initiative and its Quality Criteria provides an example of how this can happen through creating space for underrepresented groups, through valuing diversity and through promoting cross-disability work. A case study from the national federation of OPDs in Nepal illustrates how representation and coordination of OPDs from local to national supports greater participation of persons with disabilities in decision making processes. A third example illustrates the role OPDs can play in providing guidance and know-how to support participation of persons with intellectual disabilities, a group particularly overlooked in decision-making.

Key lesson 4:
Movement building requires dedicated attention to inclusion of underrepresented groups AND creating opportunities for diverse constituencies to work together and build a cohesive voice.

Promoting a diverse disability rights movement inclusive of most marginalized groups through technical capacity building – the IDA-IDDC Bridge CRPD-SDGs training initiative

The [Bridge CRPD-SDGs training initiative](#) is a unique inclusive capacity development initiative by the International Disability Alliance (IDA) and the International Disability and Development Consortium (IDDC), with support from other partners. The initiative aims to build a critical mass of disability activists able to engage as interlocutors of their governments and decision makers towards the effective implementation of the CRPD for all persons with disabilities. The training curriculum supports participants to develop an inclusive and comprehensive CRPD perspective on development, including the agenda 2030 and SDGs, and to reinforce their advocacy for inclusion and realization of all human right for all persons with disabilities.

Intervention

To do so, the initiative took a deliberate stance on diversity and set for itself high objectives to include underrepresented groups of persons with disabilities[35], and demonstrate meaningful inclusion of all across the training. This includes, among others:

- [Quality Criteria](#) to ensure diversity of the group of participants, including representation of all disability constituencies, no more than 20% of a given constituency, 25% youths with disabilities, 10% older persons with disabilities, at least 40% of either men or women, attention to rural/urban diversity and indigenous identity (where relevant).

- Preparatory meetings with representatives of underrepresented groups to ensure a smooth kick-off of the training using different inclusive facilitation techniques and tools; in addition, support personnel, such as Sign language and guide interpreters also benefit from a briefing on how to be more inclusive and prepared to the Bridge methodology.

- Valuing diversity, personal experiences and joint work among participants as key components of the learning

- Monitoring inclusion of all participants during the training

- Ensuring underrepresented groups are part of the Bridge CRPD-SDGs Training of Trainers.

Outcomes

Between October 2015 and December 2021, Bridge CRPD-SDGs reached **1146 people** from **104 countries**. Among this, **156 were facilitators** (54% being women and 33% from underrepresented groups), **469 were participants** (51% being women with disabilities and 48% being from underrepresented groups), **79 were observers** (7%) and **432 were support persons** (38%).

In addition, with the principle of inclusion forming a central theme, Bridge interpretation has been provided in 15 spoken languages, 24 National Sign Languages, International sign & tactile sign as well as illustrators, Captioning and Braille. The pool of Bridge CRPD-SDGs facilitators now includes facilitators with intellectual disabilities, with autism and with deafblindness, which plays a powerful role in demonstrating that inclusion of underrepresented groups is possible and beneficial to all.

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35   In the context of the Bridge CRPD-SDGs training initiative, the term 'under-represented groups' covers those among persons with disabilities who enjoy less visibility in decision-making processes. The disability movement, like other social movements, is not homogenous. Some groups have traditionally been less included in participatory processes, or harder to reach, or face higher barriers to participation. They include, among others, persons with deafblindness, persons with intellectual disabilities, persons with psychosocial disabilities, persons with autism or deaf people. It can also include those who may be less engaged in decision-making, such as women, children, older people and indigenous peoples, as well as people from diverse faith, ethnicity, caste, class, sexual orientation or gender identity minorities. This understanding may differ in different countries, culture and contexts

External evaluations highlighted the transformative effect of Bridge CRPD-SDGs, with a majority of Bridge alumni reporting how the skills acquired supported their daily advocacy and played a role in their OPDs securing better impact. Alumni noted that Bridge CRPD-SDGs contributed to their development on both professional and personal levels as well as of their OPDs. Further it made them better at influencing national and international public policies, more self-confident about their own expertise and value as advocates and leaders of the disability movement, and enabled creation of friendships and networks, among others. Most alumni further went on to train/ mentor others in the OPD movement and beyond[36].

A particular impact on movement building is the transformative effect on participants' attention to representation and inclusion of all constituencies. As expressed by one of the respondents to the Bridge alumni survey in 2020 "I changed as a human being. I am now more aware, respectful and supporter of the diversity of humanity."

Key lesson 5:
Movement building requires mechanisms that strengthen and value representation from grassroots level up

Strengthening geographical representation of disability rights movement and coordination from local to national levels – A case study by the National Federation of the Disabled Nepal (NFDN)

The National Federation of the Disabled Nepal (NFDN), established in 1993 is an umbrella OPD that has been leading disability rights movements in Nepal. It is run by persons with disabilities and has more than 331 member organizations in 76 districts. As Nepal moved from being a monarchy to becoming the Federal Republic of Nepal, the country started the process for a new Constitution, which not only created a huge opportunity for OPDs to advocate for inclusion of the disability agendas in the new Constitution, but also led NFDN to restructure its governance and provincial representation towards stronger geographical representation and more effective advocacy.

Intervention

NFDN led a nationwide advocacy campaign through the engagement of OPDs and other stakeholders working on disability rights, supported by DPOD-Denmark, FFO-Norway, and UNDP:

At the central level, NFDN advocated with the members of the Constitutional Assembly (CA) and its the various thematic committees as well as major political parties.

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36   Impact of the Bridge CRPD-SDGs Initiative on the use of the CRPD and the SDGs to influence public policies and reinforce DPO activists' capacities, Bridge CRPD Alumni survey, 2020

This included organizations of dialogues with OPDs, relevant stakeholders, lawyers, and lawmakers on the agenda of issues to be incorporated in the new Constitution; an SMS text message campaign to generate greater awareness among CA members on disability issues; and advocacy teams of OPDs with representation from different groups, including women with disabilities, who met with political parties, CA members, and influential leaders.

At the local level, member OPDs were urged to raise their voices locally and write letters to the CA through their respective district administration offices. Once the draft of the new Constitution was released, NFDN mobilised about 300 OPDs from all districts to take part in the consultation process at the local level to contribute to the public call for feedback.

The new Constitution of the Federal Democratic Republic Nepal, passed in September 2015, includes for the first-time clear provisions on the rights of persons with disabilities, including non-discrimination on the basis of disability and special provisions to ensure participation of persons with disabilities in federal and provincial parliament. It also requires concerned governments to adopt dedicated laws and policies to ensure equal participation and representation of persons with disabilities in decision-making processes.

The new Constitution of Nepal divided the country into 7 Provinces, 77 districts, and 753 local units, with a strong decentralization process strengthening the power of province and local governments. This created an opportunity for the disability rights movement to intervene in policymaking at decentralized levels. However, with no formal structure at the provincial level, NFDN felt constrained in mobilizing OPDs for policy advocacy. In 2017, the General Assembly of NFDN therefore amended its statutes and established a direct structure at the provincial level. FFO-Norway and DPOD-Denmark, along with MyRights, CBM and UNDP provided support to this campaign.

Subsequently, NFDN established its offices in the headquarters of each province, elected a provincial committee and supported provincial offices through training, coaching, mentoring, and information support. These committees mapped the status of policy formulation in each province and prioritized budget advocacy and provincial disability policies as key issues. Provincial offices mobilized OPD leaders and conducted a series of meetings with the Ministry of Social Development, Office of Chief Minister, Planning Commission, and Ministry of Finance, and conducted orientation sessions for the government authorities on the disability legal frameworks developed by the federal government. The advocacy groups met with parliamentarians at the provincial level and raised their issues in the media.

Outcomes

This practice illustrates efforts of a national umbrella federation of OPDs to restructure itself towards better geographical representation, coordinating the disability rights movement across decentralized structures and seizing this opportunity for more consistent advocacy from local to national level, also paying more attention to women with disabilities' representation. Through a more cohesive movement, OPDs are more effective to secure greater participation for disability-inclusive policy development. The practice created a movement led by OPDs that resulted in the inclusion of disability in the new Constitution.

As a result of the advocacy at the provincial level, a budget on disability was allocated by the provincial governments in their annual policy and budget.

Key lesson 6:
Inclusion of underrepresented groups, such as persons with intellectual disabilities, can only happen with proactive efforts to listen, include, and respect their voices and perspectives

Developing guidelines for participation of persons with intellectual disabilities by persons with disabilities – a case study by Down Syndrome International and Inclusion International

Down Syndrome International (DSi) and Inclusion International (II) are working together on 'Listen Include Respect', a joint process to develop international guidelines for inclusive participation of persons with intellectual disabilities. As the leading global OPDs representing people with intellectual disabilities and their families, they developed an inclusive process for the development of these guidelines that harnesses the knowledge of global OPDs networks across a wide variety of countries and contexts. The guidelines are designed based on the lived experiences of people with intellectual disabilities, while also being responsive to the practical questions that organizations (both OPDs and mainstream organizations) seeking to include people with intellectual disabilities commonly ask.

The data collection phase of the development of these guidelines collected input from over 1,500 people with intellectual disabilities, their families, and other stakeholders from 109 countries, with focus groups of people with intellectual disabilities coming together in 30 countries to reflect on barriers to inclusion and providing insights on the content and format of the guidelines.

The project also engaged persons with intellectual disabilities as paid staff throughout the process, including as paid consultants to give feedback on the guidelines and as core members of the 'Listen Include Respect' team.

A reference group of 20 people with intellectual disabilities and their families was also created, who guided DSi and II throughout the process through regular meetings, providing oversight to ensure the process followed is as inclusive as possible.

The result has been a process that is controlled, owned, and led by persons with intellectual disabilities and their representative organisations, with persons with intellectual disabilities involved at every stage. The project is also documenting the process and will be sharing its reflections and recommendations alongside guidelines, which are yet to be finalised to ensure learnings are shared with the larger networks and stakeholder community. Once developed the guidelines will be a milestone in fostering inclusive programming for persons with intellectual disabilities. It is also worth mentioning that process of development of these guidelines has supported testing inclusive practices through review of documents, survey platforms, co-producing webinars with self-advocates, among others. These examples are already creating a knowledge base for inclusive practices even before the guidelines are finalised.

Case studies on participation as a co-production: working together

Participation (as a co-production between OPDs invited to contribute and decision-makers soliciting their insights and expertise) is a two-way process and requires making way for new collaborations, including adaptations and changes in ways of working. This includes transforming programming work to ensure engagement of OPDs as partners across the project (inclusive programming), creating space for consultation in policy making and advisory work, and building new partnerships and innovation.

Inclusive programming

OPDs are often invited to participate in programmes that have already been designed without their inputs and mostly to support outreach and awareness activities. This part explores what works to ensure leadership and participation of OPDs across the project, program, or policy cycle, across all stages. Case studies below present an example of inclusion a systemic approach taken by the United Nations through the UN Disability Inclusion Strategy. Other important initiatives include shifting away from traditional roles for OPDs as sub-grantees or recipients to actors with a leading role in consortium projects. Since 2017, IDA has engaged in joint programming with its members, forming entirely OPD-led consortium projects. Together for Inclusion (led by the Atlas Alliance and funded by NORAD) is another example of Norwegian OPDs joining forces with large Norwegian NGOs to deliver a ground-breaking programme in six African countries. Concrete illustrations of what this means in practice is showcased in the second practice below through the experience of the Inclusion Works consortium.

Key lesson 7:
Systemic commitment including substantive and regular collaboration with OPDs across programming stages are required to transform how organizations include persons with disabilities.

The United Nations Disability Inclusion Strategy (UNDIS) –
A systemic strategy including accountability on consultation with persons with disabilities by the UN

In June 2019, the UN Secretary General launched the United Nations Disability Inclusion Strategy (UNDIS), providing the UN system with a new impetus, and related instruments including a strategy and an accountability framework, in order to accelerate the way the UN system includes and responds to the rights of persons with disabilities. The UNDIS provides the foundation for sustainable and transformative progress on disability inclusion through all pillars of the work of the United Nations: peace and security, human rights, and development. It covers four main areas of engagement: (1) leadership, strategic planning and management, (2) inclusiveness, (3) programming and (4) organizational culture.

Of particular importance is indicator 5 on consultation with persons with disabilities, which accounts for the commitment to measure steps and progress towards meaningful OPD engagement in the work of the UN. This indicator sets strong standards, with a requirement for "Systematic close consultation with and active involvement of organizations of persons with disabilities on all disability-specific issues and broader issues" and for "guidelines for consultations (to be) in place".

In 2020 and 2021 reporting shows there is room for progress. Many UN entities reported that they consulted organizations of persons with disabilities. However, as most entities did not have consultation guidelines, a criterion for approaching the requirements of this indicator, 80% of UN entities reported missing requirements. To support improvement, the UNDIS team, in partnership with the International Disability Alliance (IDA), developed guidelines on how to consult with and actively involve persons with disabilities and their representative organizations in all disability-specific and general decision-making processes across the UN's work. Among others, the guidelines identify eight key considerations on meaningful participation, aligned with recommendations from the CRPD General Comment 7:

- OPDs should be consulted through a variety of appropriate, context specific methodologies;

- Consultations should aim to engage with the diversity of the population of persons with disabilities and consider intersectionality;

- OPDs should be engaged as partners in the planning, design, and implementation of consultations;

- Consultations should be accessible and reasonable accommodation needs to be provided;

- Consultations should be based on transparency, meaningful dialogue, and good faith;

- OPDs should be adequately supported for their participation, including through timely information, capacity building and funding;

- Consultations should be safe, empowering, respectful, and not tokenistic;

- Knowledge and learning generated by consultations should be considered and outcomes should be shared with OPD.

Key lesson 8:
Identifying focal points supporting constant engagement of OPDs across project stages can help securing a space and influence for OPDs within large consortium projects

Operationalising meaningful OPD engagement in a development project – Making engagement open and accessible to a diversity of groups – A case study by the Inclusion Works consortium

The Inclusion Works consortium project is part of the Inclusive Futures initiative,[37] and led by Sightsavers. The project focuses on testing innovative ways to improve economic empowerment and inclusion for people with disabilities in the formal sector in Bangladesh, Kenya, Nigeria and Uganda. At the onset of the project, through the role of IDA in the governance of the project and involvement of other global, regional and national OPDs as partners[38], it was flagged that preconditions for participation of OPDs were not met, including a lack of knowledge from partners about how to engage with persons with disabilities, compounded by the lack of funding for reasonable accommodation. Space for participation of underrepresented groups was fairly limited.

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37 Inclusive Futures is funded by UK Aid and works to ensure that all adults and children with disabilities have the same likelihood as everyone else to access quality health, education, and work opportunities.

38 The International Disability Alliance (IDA) is a member of the Inclusion Works Core Group and formed an Inclusive Livelihoods Task Team as an advisory group to support this role, including Inclusion International, Down Syndrome International, the World Blind Union, the African Disability Forum, the International Federation of Hard of Hearing, and the World Federation of the Deaf. This group also reflected and advised meaningful engagement of country level OPDs.

Intervention

To address this, the Inclusion Works program piloted an OPD engagement mechanism to ensure OPDs could take part more meaningfully.

At the design stage, attention was drawn by OPDs to the need to ensure diverse OPD representation at in-country workshops, and local OPD participants provided support and feedback using a participation and accessibility checklist.

- At the stage of partner selection, the programme set an open call whereby OPDs could apply to be implementing partners in the IW programme, creating opportunities for OPDs not traditionally partners of INGOs to apply; the call was actively disseminated to organisations of women with disabilities and those from underrepresented groups and included flexible conditionalities for funding to lift typical barriers (such as not having adequate administrative strength).

- To support implementation, national OPD Engagement Officers (OPD EOs) were hired in each project country to spearhead coordination of OPD engagement in the project, pay attention to participation of underrepresented groups and support programme activities to reflect standards set by the CRPD. The positions were hosted within the national umbrella federation of OPDs (where it exists) and persons with disabilities with expertise on CRPD and strong connections to the national disability movement were hired in the 4 countries.

- Coordination on OPD participation in the project by OPD Engagement Officers was supported by the foundation of National Project Advisory Committees or NPAC (OPD-led advisory bodies) that fostered greater connect with the larger disability movement on issues around inclusive employment aimed at creating greater buy-in on project achievements.

Outcomes

Putting diversity of persons with disabilities at the centre of programming, including by creating enabling conditions for such groups to participate, the OPD selection process created enabling conditions for such groups to participate, which resulted in the inclusion of underrepresented groups. The OPD EOs have been seen as a resource of change at the country level. They have been consulted by partners on a diversity of issues and have supported and advised on programme activities facilitating the engagement of persons with disabilities across all programme levels, including underrepresented groups, leading to increased diversity in disability constituencies from the 2nd year.

The OPD EOs participate in regular creation of resources on CRPD and meaningful OPD engagement, and support OPDs to be at the centre of activity implementation, and to lead advocacy.

This model has been adapted by another project within the Inclusive Futures consortium/ Disability Inclusive Development (DID) in Nigeria, which a similar OPD selection process. OPDs were invited to apply through an open call for expression of interests, which were reviewed by a selection committee involving the lead international NGO (Sightsavers), a regional OPD (the African Disability Forum) and a global OPD network (the International Disability Alliance).

Inclusive policy making and advisory work

This section looks at what works to ensure that the perspectives of OPDs are effectively included in policy making. Case studies illustrate diverse roles OPDs can play to influence policy response. The first practice shows OPDs' success in making Covid-19 responses disability-inclusive in Kenya through the use of data and evidence-based advocacy. The second reflects OPD's roles in transforming the response to persons with psychosocial disabilities in Indonesia.

Key lesson 9:
OPDs can play a critical role in addressing evidence gaps that impact how public policies and programs are designed and implemented

Using the data-driven advocacy approach to guarantee inclusion of persons with disabilities in society – A case study by United Disabled Persons of Kenya (UDPK)

Policy needs to be informed by evidence, and in many contexts, the lack of reliable data on disability has been one of the underlying causes for the absence or deprioritization of persons with disabilities in policy making. In Kenya, although the Kenyan government has made efforts to consider persons with disabilities when making laws and policies, often this is done as an afterthought, and their representative organizations OPDs have had limited involvement of persons with disabilities in the drafting of laws and policies. This became more evident during the COVID-19 pandemic as the lack of involvement of persons with disabilities in the government response to the pandemic resulted in the failure to capture the unique challenges faced by persons with disabilities. Dissemination of information about the pandemic was often inaccessible to a wide range of people. Persons with disabilities faced heightened risks of infection and once infected, also were confronted with the inaccessibility of most health services

Further, persons with disabilities were not prioritised in vaccination schedules, making this group even more vulnerable. In this context of crisis affecting the entire country, strong evidence was needed to convince the government to act.

This case study details the strategy adopted by United Disabled Persons of Kenya (UDPK), umbrella federation of 200 member OPDs established in 1989, in convincing Kenya's government to address persons with disabilities in its response to the pandemic.

Intervention

UDPK was introduced to Data-Driven Advocacy in 2019 through the UK Aid funded Innovation to Inclusion programme (i2i Initiative) and started implementing the approach to influence change in the community. It collected data from government sources and used it to formulate data-driven advocacy strategies. For instance, by mapping its data collection around social protection and identifying the gaps in alignment of existing social protection measures with the CRPD, UDPK wrote a policy brief and raised the issues with the government line ministry.

Based on this data-driven advocacy approach, it worked with partners through social media campaigns as well as by writing petitions, memoranda to the Ministry of Health and Ministry of Social Protection, urging them to consider persons with disabilities in COVID-19 interventions and programmes. This was complemented by the creation of forums with government line ministries to bring persons with disabilities to the centre of the Kenyan government's response to COVID-19.

As a result of these interventions, the government increased its efforts to provide accessible information about COVID-19 to persons with disabilities, including by providing inclusive services such as Kenyan Sign Language Interpreters in briefings. Efforts were also made to provide COVID-19 Information Communication Materials in accessible formats. UDPK also started seeing the inclusion of persons with disabilities in the County COVID-19 Response Committees which ensured needs of persons with disabilities were considered as approaches were developed.

UDPK also advocated for prioritisation of persons with disabilities in the vaccination programme. Since there was no disaggregated government data to show the number of people with disabilities who were still to receive the vaccine, UDPK mobilised its network of OPDs to capture this information.

Outcomes

All this resulted in reduction of the number of new infections in persons with disabilities through adapted preventative behaviours and also ensured that the group knew what to do or where to seek help in case of infection. Getting necessary information reduced anxiety and improved psychosocial wellbeing. The presence of representatives with disabilities in Kenya's County COVID-19 Response Committees ensured the unique needs of persons with disabilities were captured at inception and reflected adequately in implementation plans ultimately mainstreaming inclusive COVID-19 responses.

UDPK was able to demonstrate how infections were increasing in this vulnerable group and as a result of this advocacy, persons with disabilities were placed in the priority category.

UDPK's approach demonstrates how the contribution of OPDs and the lived experience of persons with disabilities can be effectively utilised in policy making and advisory work. The support to UDPK to lead data-driven advocacy not only made it easier for persons with disabilities to engage with duty bearers but also complimented government efforts in gathering necessary evidence and filling crucial data gaps during a time-sensitive health emergency. The practice is a good example of the role OPDs play in leading advocacy and playing an advisory role to ensure voices of persons with disabilities are counted in policy making.

Key lesson 10:
OPDs, including from underrepresented and marginalized groups, can mobilize community voices and create demand for policy change impacting persons with disabilities

Multiple tactics, many allies: fighting for freedom of persons with psychosocial disabilities in Indonesia – a case by Perhimpunan Jiwa Sehat/Indonesian Mental Health Association (IMHA)

Persons with psychosocial disabilities continue to be one of the more marginalised groups of persons with disabilities and face tremendous systemic barriers to come together and build a collective voice. In Indonesia, a vast number of people with psychosocial disabilities are trapped in "social care" institutions, where they experience solitary confinement. Inhumane treatments, physical and mental abuse, sexual violence and harassment, and other acts that degrade human dignity are rampant in such institutions, and neglect was further aggravated during the COVID-19 pandemic. While there is growing recognition of the need to enact emergency deinstitutionalization plans, including adopting an immediate ban on institutional admissions during and beyond the pandemic, and the transfer of funding from institutions to community support services, implementation has been poor.

The Indonesian Mental Health Association (IMHA) or Perhimpunan Jiwa Sehat in Bahasa, IMHA is the first organization of persons with psychosocial disabilities in Indonesia and has been working to address some of these issues through policy advocacy[39]. This case study shows how investments to support OPDs to lead policy advocacy work can shift the needle on inclusion of persons with disabilities, particularly for underrepresented groups.

Intervention

IMHA, combined multiple tactics to address this situation:

- It successfully advocated for the establishment of a support centre for persons with psychosocial disabilities in South Jakarta. This centre became the first centre funded by the Indonesian government that is not a residential institution or a psychiatric hospital.

- IMHA further advocated to the Constitutional Court in 2016 to enable persons with psychosocial disabilities to vote for the first time in regional elections in 2017 and in 2018 and ensured that persons with psychosocial disabilities were able to exercise their right to vote in the national general election, including around 3,000 persons with psychosocial disabilities who live in residential institutions.

- Submitting a CRPD Alternative Report on the situation of persons with psychosocial disabilities in Indonesia, IMHA succeeded in getting their issues highlighted by the CRPD Committee in their List of Issues for the Indonesian government.

- In response to COVID-19, IMHA repurposed funding to launch a multimedia campaign in partnership with Human Rights Watch to raise awareness on the implications of COVID-19 for persons with psychosocial disabilities who are confined to institutions, resulting in an on-going dialogue with officials to improve conditions, and private sector support for access to COVID-19 testing inside institutions.

- A platform was also established to shift community and governmental attitudes away from institutional and medically focused interventions towards community-based and user-led services that support a rights-based approach aligned with the CRPD.

- Currently, IMHA is filing an appeal in the Constitutional Court to overturn Civil Code KUHP Article 433 with the help of a wide variety of actors. Article 433 allows for involuntary admissions to institutions leading to violence, abuse and degrading treatment, while denying persons with disabilities the right to inheritance, work, or a family and political rights.

- Desk research on documented cases of denial of legal capacity of persons with psychosocial disabilities in Indonesia has been conducted to support the appeal in the Constitutional Court and the OPD is working with lawyers led by the Centre on Law and the Constitution at the National Islamic University of Indonesia. The review has been supported by Komnas HAM (National Commission on Human Rights) and ten other organizations, including OPDs, who prepared the case analysis. The appeal will be submitted at the beginning of 2022.

Outcomes

The practice demonstrates how OPDs can lead effective strategies on policy advocacy for systemic changes rather than being passive stakeholders, particularly in the case of underrepresented groups. In this case, consistent and flexible donor funding - allowed IMHA to develop its capacity to address the abuse, violence, and degrading treatment that persons with psychosocial disabilities face while living in institutions. It also created the space for the OPD to expand its approaches (research, advocacy, campaigning, and legal means), effectively reinforcing the role of OPDs to provide technical support and expertise. It is also worth mentioning that IMHA also built partnerships both within and outside the disability community. Effective mobilization allowed IMHA to get commitments towards its work for deinstitutionalization from women's rights groups, legal aid organizations, ministries, the National Human Rights Institution (NHRI), and elected representatives resulting in the establishment of a working group.

Creating new partnerships and transforming practices

Meaningful participation of OPDs requires a transformative shift in how organisations inherently approach inclusive development and humanitarian action. This includes moving away from looking at disability as a niche issue to something that is inalienable from the principle of 'leave no one behind'. Case studies below relate to innovative practices to stimulate OPD engagement through creating new platforms, coalitions and consortiums involving or motivating new stakeholders to engage in the promotion of rights of persons with disabilities.

Key lesson 11:
Greater impact can be leveraged through partnerships between OPDs and larger organizations (such as the UN) that respect and build on OPDs' priorities

Promoting participation through collaboration between OPDs and the UN – A case study by IOM Iraq and Iraqi Alliance of Disability Organizations (IADO)

Iraq has one of the largest populations of persons with disabilities in the world.[40] Persons with disabilities in Iraq are disproportionately impacted by war, armed conflict, terrorism, violence and the economic hardship. The Federal Government of Iraq, Kurdistan Regional Government, United Nations agencies, international non-governmental organizations and civil societies are making efforts toward addressing the multiple, intersecting barriers faced by persons with disabilities.[41]

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40   Committee on the Rights of Persons with Disabilities media release on the impact of the armed conflict on persons with disabilities in Iraq. 2019a.

41   United Nations Assistance Mission for Iraq (UNAMI)/Office of the High Commissioner for Human Rights (OHCHR), 2016a, Report on the Rights of Person with Disabilities in Iraq. UNAMI/OHCHR, 2016a.

Unfortunately, these efforts have been hampered by a lack of resources, competing institutional priorities, insufficient institutional will and the prevalent use of the charity approach, where persons with disabilities are pitied, rather than empowered, through a rights-based approach to disability inclusive mainstreaming. The Iraqi Alliance of Disability Organisations (IADO) is the national umbrella OPDs in Iraq, with around 30 member OPDs across majority of the 18 governorates in Iraq. IADO receives little to no support from government, humanitarian and development agencies to carry out its mandate, and therefore struggles to offer capacity building opportunities to under- represented groups including women with disabilities and Deaf people.

Intervention

In March 2020, IOM Iraq began collaborating with IADO to gain a better understanding of its priorities. IADO shared that one of its priority areas was to offer more support to national committees of underrepresented groups. Based on this, in September 2020, IOM Iraq prioritized support to three IADO national committees (blind committee, deaf committee and women's committee) to increase their ability to represent their respective impairment groups throughout Iraq. This included capacity building support covering variety of topics including leadership, communication, advocacy, evidence-based approach and proposal writing, in addition to other topics requested by the three committees. Committee members reported increased confidence in communicating with their target audiences. The practice was replicated in January 2021 to support OPDs based in Erbil, leading to greater collaboration among Erbil-based OPDs who prepared communication about their priorities to the Government in a forum funded by IOM.

In parallel to this, in response to IADO priorities, IOM Iraq recruited an Assistant seconded to IADO to support their coordination and communication with OPDs in Iraq. This role sat inside IADO and set up meetings, supported reasonable accommodations, inviting guest speakers for national OPDs meetings and led regular communication between OPDs through WhatsApp. The Assistant also supported a mapping of OPDs to produce a directory of contacts of over 60 OPDs. The mapping supports both greater communication between OPDs in Iraq, but also assists collaboration between OPDs and humanitarian and development agencies in Iraq. It supports outreach to OPDs across the country, as demonstrated through the joint call circulated by IOM and IADO for the Bridge CRPD-SDGs training which received the largest number of applications that Bridge CRPD-SDGs ever received for any country/region.

Outcomes

This practice illustrates positive outcomes from efforts combining interventions that resulted from consulting with IADO on their priorities. Tailored capacity building including attention to underrepresented groups, OPD mapping through a position seconded within IADO created opportunities for OPDs across Iraq to enhance communication and coordination.

The partnership with IOM made it possible to leverage the convening power of the UN with the government to organize a round table with the Federal Government of Iraq including Deputy Minister of Labour and Social Affairs, and around 20 Heads of Ministries who form the Commission for Care of Persons with Disabilities and Special Needs in Iraq.

Through this roundtable, IADO discussed with decision makers the barriers experienced by persons with disabilities and challenges and priorities of OPDs in Iraq (captured in the Persons with disabilities and their representative organizations in Iraq: Barriers, Challenges and Priorities report)

Key lesson 12:
Through alliances and networking between partners and allies across different social movements, OPDs can contribute improve relevance of interventions towards population groups more at risk of seeing their human rights violated

Addressing intersectional discrimination and invisibility of underrepresented groups: Mexico Coalition for the Rights of Persons with Disabilities (COAMEX)

Persons with disabilities often face multiple forms of discrimination, which can get further compounded when it intersects with other identity factors, such as age, gender, indigenous identity, etc. Human migration is an area identified as a source of discrimination and vulnerability, yet disability has rarely been considered in interventions towards migrants. In 2014, the Committee on the Rights of Persons with Disabilities expressed to the Mexican State its concern regarding the prevalence of intersectional discrimination and the invisibility of certain groups, referring to the cases of Central American migrants. The Mexico Coalition for the Rights of Persons with Disabilities (COAMEX) mobilized resources and strategic partnerships with like-minded organisations to impact the situation of migrants with disabilities in six countries of the Mexico-Central America strip.

Intervention

COAMEX is a coalition of a group of organizations made up of people with and without disabilities that support the rights of people with disabilities in Mexico and their inclusion through the policies carried out by the government. With the support of the Pan American Development Foundation (PADF), COAMEX launched a project titled 'Migration and Disability: Follow-up to the implementation of the CRPD in Mexico and Central America'. This project carried out an investigation to understand how social factors, economic situations, and the context of generalized violence experienced in the region interact and force people with disabilities to participate more actively in the phenomena of human mobility.

This research was carried out over a period of 19 months during which 101 interviews were collected with persons of interest and humanitarian actors from 36 shelters in 31 municipalities in Mexico, El Salvador and Honduras. This qualitative study enabled the identification of the level of compliance with the CRPD and the Global Compact for Safe, Orderly and Regular Migration, which also allowed the drafting of the Special Report on Migration and Disability. This enabled COAMEX to influence the Committee to include specific questions on migration, refuge and disability on the List of Issues for the Mexican State in 2019.

That same year, COAMEX with the support of the Latin American Network of Non-Governmental Organizations of Persons with Disabilities and their Families – RIADIS, held a parallel event within the framework of the Global Disability Summit in Buenos Aires, Argentina where it shared the results of the research and influenced the decision, "Buenos Aires Agreements - Protection of the human rights of persons with disabilities in conditions of migration, asylum, refuge and forced displacement". It called on the governments to ensure protection and safeguarding measures for migrants and asylum-seekers and refugees with disabilities.

Outcomes

With these actions, COAMEX proved to be a model in the region to promote new collaborative platforms that generated actions around this thematic intersection, deepening advocacy for the cause and highlighting the situation of people with disabilities and their needs in Latin America. This fostered further partnerships/ synergies with RIADIS and the Regional Office of the United Nations High Commissioner for Refugees (UNHCR) developing a regional report on the theme in 2020 and COAMEX partnering with them for data collection and analysis of information for Mexico and Central America.

Although COAMEX began as a collective of Mexican organizations that sought to follow up on the implementation of CRPD in their country, the practice shows how it was able to reinvent itself to face other global and regional challenges, creating strategic alliances with organizations of and for persons with disabilities in Central America. The research resulting from the Migration and Disability project helped establish the foundations for other initiatives of impact at the community level, such as the projects Promoting the Labour Rights of Persons with Disabilities in Central America (with the support of PADF) and promoting inclusive approach in the contexts of human mobility in Central America in collaboration with CBM International.

COAMEX's experience in the last five years shows the potential role that establishment of strategic alliances can play at the regional level. This raised the profile of OPDs within the migration discourse and supported resource mobilization and exchange of learning from local to regional levels. Networking between partners and allies across different social movements also led to more effective advocacy platforms, and generally strengthened response mechanisms towards population groups more at risk of seeing their human rights violated.

Summary of key lessons from case studies:

- **Key lesson 1:** Organisational capacity development supports OPD leadership, capacity to forge partnerships.

- **Key lesson 2:** Technical capacity development of OPDs leads to mutual benefits and reinforcement of OPDs and partners towards better impact.

- **Key lesson 3:** Technical capacity development is a process that requires sustained support and leads to greater recognition of OPDs' added value to development.

- **Key lesson 4:** Movement building requires dedicated attention to inclusion of underrepresented groups AND creating opportunities for diverse constituencies to work together and build a cohesive voice.

- **Key lesson 5:** Movement building requires mechanisms that strengthen and value representation from grassroots level up.

- **Key lesson 6:** Inclusion of underrepresented groups, such as persons with intellectual disabilities, can only happen with proactive efforts to listen, include and respect their voices and perspectives.

- **Key lesson 7:** Systemic commitment including substantive and regular collaboration with OPDs across programming stages are required to transform how organizations include persons with disabilities.

- **Key lesson 8:** Identifying focal points supporting constant engagement of OPDs across project stages can help securing a space and influence for OPDs within large consortium projects.

- **Key lesson 9:** OPDs can play a critical role in addressing evidence gaps that impact how public policies and programs are designed and implemented.

- **Key lesson 10:** OPDs, including from underrepresented and marginalized groups, can mobilize community voices and create demand for policy change impacting persons with disabilities.

- **Key lesson 11:** Greater impact can be leveraged through partnerships between OPDs and larger organizations (such as the UN) that respect and build on OPDs' priorities.

- **Key lesson 12:** Through alliances and networking between partners and allies across different social movements, OPDs can contribute improve the relevance of interventions towards population groups more at risk of seeing their human rights violated.

4 Part 4

Conclusion and recommendations to secure and enhance meaningful engagement of Organisations of Persons with Disabilities (OPDs)

This section reflects on the above framework, stock-taking and case studies to draw key learning and recommendations on 'how to' ensure meaningful OPD engagement. As this paper was developed, the parallel process of building recommended commitments for the 2nd Global Disability Summit was going on and a dialogue was established between contributing groups, and the two processes mutually influenced and reinforced each other. The last part of this paper therefore presents the GDS menu of commitments on OPD engagement, as a list of direct actions that can be taken by governments, donors, civil society, private sector or OPDs.

'How to' ensure meaningful OPD engagement

While this paper does not intend to be a practical guide for disability-inclusive programming, the examples above allow to identify important components on the 'how to' ensure meaningful OPD engagement in practice:

1   **A twin-track approach:** Targeted interventions to invest in OPDs and equalize their opportunities to act as partners and development interlocutors, combined with clear efforts to transform ways of working and 'make way' for meaningful participation in program, policy and practice. This creates a virtuous circle whereby OPDs increasingly acquire experience and capacities to engage and become more efficient counterparts. Policy engagement is essential to set inclusive agendas and priorities, and government have a critical role to play in holding space for OPDs to engage with local government.

2   **Particular attention to underrepresented groups of persons with disabilities:** The commitment to leave no one behind requires attention to groups most at risk of being excluded from consultation and participation, because they lack self-representation or access to information and opportunities. This includes persons with intellectual disabilities, persons with psychosocial disabilities, persons with deafblindness, autistic persons, women with disabilities, youths with disabilities and indigenous people with disabilities, as also persons with disabilities in emergency and crisis situations and those living with chronic conditions, HIV/AIDS, among others. Proactive efforts are needed to reach out to these groups and ensure that conditions are ensured for their participation.

3   **Support to movement building:** OPD engagement should be supported in ways that strengthen the disability rights movement as a diverse and unified representation of persons with disabilities. This means, for example, respecting and consolidating the mandate of umbrella federations[42] as the coordinated voice of persons with disabilities towards governments, while supporting transparency, diversity and accountability of representation and leadership, in particular leadership of women and youth with disabilities. Programs working with a single constituency or OPD should be mindful of the 'bigger picture' to not be detrimental to the building of a 'common voice'.

4   **Anticipation and resourcing of participation across all stages:** Meaningful OPD engagement is a commitment requiring mechanisms at every stage of the program, project or policy cycle, to ensure relevance and accountability of interventions to persons with disabilities. This requires anticipation, including budgeting for accessibility, reasonable accommodation and the roles of OPDs as partners where relevant. Mechanisms to engage with persons with disabilities as recipients of aid (such as feedback loops, testimonials etc.) are important for programmes to understand their impact on persons with disabilities, yet they should not replace participation through OPDs as organized representative bodies. Diverse strategies and mechanisms exist such as supporting OPDs to prepare their contribution into project/ policy design, involving OPD representatives in steering committees and project governance, setting mechanisms for OPDs to coordinate their feedback, mobilizing OPDs in evaluations, etc. In emergency, anticipated strategies through inclusive disaster risk management and contingency plans also prepare the ground for more inclusive responses with a role for OPDs (together with flexibility in funding, see below).

5   **Feedback and meaningful dialogue:** Valuing inputs and contributions from OPDs, providing feedback on how their concerns and priorities were incorporated is part and parcel of OPD engagement that shifts away from tokenism and box-ticking. This contributes to building trust and can support OPDs to understand how they can be most efficient in channelling their views. Participation creates opportunities for mutual learning, and opportunities for OPD partners to become more inclusive of all.

6   **Flexibility:** As organizations representing a discriminated group, OPDs often don't meet the conditions to access funding and roles in projects. As highlighted in the case studies, flexibility from donors can make a huge difference in enabling participation.

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42   Umbrella organizations of persons with disabilities are coalitions of representative organizations of persons with disabilities. They accept all organizations of persons with disabilities as members, representing a wide diversity of persons with disabilities, and be organized, led and controlled by persons with disabilities; and speak on behalf of their member organizations on matters that are of mutual interest and collectively decided upon (GC 7, CRPD Committee).

This includes adapted conditionalities for funding, such as fiscal sponsorship of a small organization by a larger one who can act as a guarantor, or flexibility in repurposing funding to new priorities – this supported for example OPD resilience in the context of the Covid-19 pandemic. This also includes systematic consideration for equity in value for money, including systematic accessibility and reasonable accommodations costs.

Recommendations on OPD engagement in the context of the Global Disability Summit

As part of a process to guide strong and ambitious pledges on OPD engagement at the Global Disability Summit 2022, the final section of this discussion paper provides a set of recommendations which could also serve the purpose of informing possible commitments by governments, donor organisations, civil society, private sector, and OPDs where relevant. This is in line with the recent proposed menu of commitments that was shared by the Global Disability Summit co-hosts to generate greater engagement in the run up to actual Summit in February 2022. The menu of commitments is intended to be a guiding document that highlights current priorities under each of the themes of GDS 2022.[43]

In keeping with this background, this paper lays down 10 recommendations under four themes that stand to foster meaningful OPD engagement.

THEME I:
Advance the disability rights movement by building a stronger and more diverse collective voice, including diversity and intersectionality

1 **Promote underrepresented groups and address intersectionality**
(Governments/ Donors/Civil Society/OPDs/Private Sector):
For instance, by strengthening and supporting the leadership and leadership development role of youth, women, ethnic minorities, indigenous peoples and other marginalized groups of persons with disabilities, including under-represented groups facing intersectional discrimination.

2 **Support partnerships with other social movements**
Governments/Donors/Civil Society):
For instance, by supporting coalition building and strategic partnerships between OPDs and mainstream organisations to promote leadership of persons with disabilities. Addressing intersectional identities and priorities, promote cross-organisation learning and build inclusive approaches to national implementation of the Sustainable Development Goals, budgetary advocacy, and human rights reviews.

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43   https://www.globaldisabilitysummit.org/pages/submit-or-update-a-commitment

THEME II:
Increase and monitor funding that goes to OPDs

3   **Increase funding to support OPDs' priorities**

(Government/Donors/ Civil Society):

By ensuring that OPDs have access to adequate core funding and resources to support their operations, organisational development and advocacy priorities and perform their role(s) with independence, autonomy and adequate capacity.

4   **Adapt funding conditionalities to OPD support**

(Government/Donors/Civil Society):

For instance, by facilitating OPDs' access to funding by ensuring that application processes are inclusive and accessible. Ensure that requirements are proportionate to the realities of the different sizes and capacities of OPDs, consider their stage in organisational capacity development, and afford appropriate flexibility in times of crisis (e.g. COVID-19), enabling access by a broader diversity of OPDs and their leadership, including smaller gras-roots-, youth-, women-led OPDs and OPDs of other underrepresented groups.

5   **Mainstream OPD engagement across funding**

(Government/Donors/Civil Society):

For instance, by ensuring that funding does not discriminate against persons with disabilities and that it actively contributes to advancing their human rights, both in development cooperation and humanitarian action. Setting as a condition for funding that projects entail clearly resourced OPD participation. Ensuring budgetary provisions for involvement of OPDs with regards to consultation and meaningful participation in projects, including budgets available for accessibility and reasonable accommodation.

THEME III:
Support OPD technical and organisational capacity development

6   **Support the building of a diverse disability rights movement and OPDs, including underrepresented groups** (Governments/Donors/Civil Society):

For instance, by supporting technical capacity development of OPDs, aligning with the Convention on the Rights of Persons with Disabilities (CRPD), including both cross-disability cohesion across diverse constituencies and targeted support to foster representation of most marginalized and underrepresented groups, and including peer support strategies among OPDs. Supporting OPDs to acquire skills and to meaningfully engage in local level, national and international policy monitoring and evaluation to influence policy to use data, statistics and budget analysis in both development and humanitarian interventions.

THEME IV:
Create conducive legal and social environments for OPDs to exist and operate

7   **Remove legal, social and other barriers to participation of persons with disabilities and their organisations** (Governments):
For instance, by repealing all laws and ending practices that prevent persons with disabilities from being considered citizens with equal rights and ensuring that OPDs are fully consulted and involved in legal issues that concern them, based on the principle of "Nothing about us without us".

8   **Commit on the need to involve persons with disabilities in countries under stress and with shrinking civil space** (Governments/Donors/Civil Society):
For instance, by engaging with persons with disabilities and their families at community level and encourage them to participate in consultation processes and decision-making bodies with local authorities. Invite them to use their knowledge of disability, (IASC Guidelines).

9   **Ensure conducive policy environment** (Governments):
For instance, by creating policy frameworks and political environments that enable the functioning of OPDs as human rights advocates and civil society organisations representing the diversity of persons with disabilities, supporting their autonomy and capacity to operate in the longer run, officially acknowledge their relevance and that consulting them early becomes routine in law, policy and decision-making and other relevant processes.

10   **Support awareness-raising to combat attitudinal barriers, either OPD-led or with the active involvement of OPDs** (Governments/Donors/OPDs/Civil Society):
For instance, by supporting initiatives and partnerships to encourage the media to portray persons with disabilities in a manner consistent with the CRPD. Supporting campaigns and initiatives that seek to change negative perceptions of persons with disabilities and ensure leadership of a diversity of OPDs on key messages. Putting in place actions that facilitate partnership between OPDs and media and social media companies that promote perceptions reflecting human rights and human dignity and challenge stigma and discrimination.

Annex A - Methodology

The International Disability Alliance (IDA) led the development of this paper in consultation with OPDs, partners and allies, including the Global Action on Disability (GLAD) network and its members, and co-hosts of the GDS 2022.

This discussion paper was commissioned by NORAD as **a contribution to unpack, frame, guide and incentivize engagement of Organizations of Persons with Disabilities (OPDs) in development and humanitarian action through the Global Disability Summit (GDS) 2022**. Leadership by IDA as a global alliance of OPDs was a way of enacting the principle of meaningful OPD engagement in the development of this discussion paper itself, and of ensuring that its content is owned and endorsed by OPDs as the first stakeholders concerned. This helped to integrate centrally in the paper the learning and experiences of IDA and its members of their own engagement as OPDs, including the findings of IDA's Global Survey on OPD participation.

However, reflecting the nature of participation, it was important that the paper would not only include an OPD perspective, but also the views of allies, partners and other counterparts in 'co-producing' participation. In this direction, a draft concept, process and document outline was proposed by IDA, discussed and agreed with the Global Disability Summit Secretariat and the Norwegian Ministry of Foreign Affairs. Subsequently, in addition to consultations led by IDA within its own constituencies (eight global and six regional networks of OPDs), two advisory groups were formed representing a diverse range of stakeholders, including a group of 5 (G5) solicited to review and comment on the draft of the overall paper[44], and a group of 3 (G3) solicited to support the screening and preselection of case studies received through an open call[45].

To ground the discussion paper recommendations into concrete examples and case studies of what has worked so far to advance OPDs' participation in development and humanitarian action, **a call for good practices/ case studies was launched in August 2021**.

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44 This group included representatives of bilateral donors (Foreign Commonwealth and Development Office, FCDO), multilateral donors (Office of the UN Disability Inclusion Strategy, UNDIS), a national OPD (Union of Disabled People of Kenya, UDPK), and international civil society actors focused on disability (International Disability and Development Consortium, IDDC)

45 This group included representatives of organizations with practical experience in running projects with OPDs, including the Disability Rights Fund (DRF), the Atlas Alliance and IDDC.

Process for the open call for case studies

The call was open to civil society organizations, consortia, networks or partnerships of organizations, private sector entities, media, donor agencies, and OPDs themselves from all countries and regions of the world, with an overarching aim to collect a diversity of experiences. Illustrating the growing interest for this topic and/or the traction of the Global Disability Summit itself, IDA received a total of 92 practices in response to this call, from more than 40 countries.

Among the entries received, 34% were submitted by OPDs, 29% were received from INGOs, 20% were received from others, which included those from associations, consortia, education institutes, 11% practices were identified by their organisations as belonging to more than one category and 7% practices were received from donor agencies. The highest number of practices were received from countries - 70%, 15% practices were multi-country in scope, 10% were global, 5% were regional in scope. If we exclude those that belonged to the category of global, 36% were from Asia-Pacific region, 33% practices were received from Africa, 12% identified as belonging to more than one region, 10% were from Latin America and the Caribbean, 7% were from Arab region and remaining 2% from Europe. The maximum number of practices (49) contributed to category 6 of 'creating new partnerships and transforming practices'; 44 entries contributed to category 4 of 'Inclusive programming'; 41 entries contributed to category 1 of 'organisational capacity building of OPDs'; 39 entries contributed to category 5 of 'Inclusive policy making and advisory work'; and 36 entries contributed to category 3 of 'technical capacity building'. Category 2 of 'movement building' received the lowest contribution from practices – 33.

The G3 screened and shortlisted practices based on the set parameters/ criteria established in the call for case studies, and after collecting further information these examples were summarized and incorporated into part 3 of this paper and associated with components of OPD engagement they illustrated the best, either on creating preconditions for OPDs to engage, or on adapting working practices and building partnerships that enable meaningful OPD engagement.

Criteria included: 1) demonstrated meaningful engagement of OPDs, 2) taking into account accessibility and reasonable accommodation, 3) promotion of active participation of underrepresented groups of persons with disabilities, 4) clear explanation of the change process, 5) evidence that the practice supports building and cohesion of the diversity of the disability rights movement.

Finally, recommendations from this paper (part 4) were also informed by the parallel process held in October and November 2021 to define the menu of commitments for the GDS on OPD engagement. This process actively involved OPDs and members of the GLAD network, including the Open Society Foundation, USAID, NORAD, FCDO, IDDC, UNDIS, the Atlas Alliance, with a final review and endorsement by the GDS co-hosts.

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