

2022 Report

# Not just ticking the disability box? Meaningful OPD participation and the risk of tokenism



Findings from the 2nd IDA Global Survey on the Participation of Organisations  
of Persons with Disabilities (OPDs)

# Table of contents

<b>List of Acronyms</b> .....	<b>3</b>
<b>Foreword by the President of IDA</b> .....	<b>5</b>
<b>Acknowledgements</b> .....	<b>7</b>
<b>Executive Summary</b> .....	<b>8</b>
<b>Part 1 – Background and Rationale</b> .....	<b>15</b>
<b>Part 2 – About the second IDA Global Survey on OPD participation</b> .....	<b>22</b>
<b>Part 3 – Key Findings</b> .....	<b>36</b>
<b>Part 4 – Recommendations</b> .....	<b>69</b>
<b>Bibliography</b> .....	<b>72</b>

## List of Acronyms

<b>ADF</b>	African Disability Forum
<b>ALL Institute</b>	Assistive Living and Learning (ALL) Institute
<b>CBM</b>	Christoffel Blind Mission
<b>COSP</b>	Conference of States Parties
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>DSI</b>	Down Syndrome International
<b>EDF</b>	European Disability Forum
<b>FCDO</b>	Foreign Commonwealth and Development Office
<b>GDS</b>	Global Disability Summit
<b>GLAD</b>	Global Action on Disability
<b>IDA</b>	International Disability Alliance
<b>II</b>	Inclusion International
<b>ILO</b>	International Labour Organisation
<b>INGOs</b>	International Non-Governmental Organisations
<b>OCHA</b>	Office for Coordination of Humanitarian Affairs
<b>OHCHR</b>	Office of the High Commissioner on Human Rights
<b>OPD/ DPO</b>	Organization of Persons with Disabilities / Disabled People Organization
<b>RIADIS</b>	Latin American Network of Persons with disabilities and their Families
<b>SDG</b>	Sustainable Development Goals
<b>UDHR</b>	Universal Declaration of Human Rights
<b>UNDP</b>	United Nations Development Programme
<b>UNESCO</b>	United Nations Educational, Scientific and Cultural Organization
<b>UNFPA</b>	United Nations Population Fund
<b>UNHCR</b>	United Nations High Commissioner for Refugees
<b>UNICEF</b>	Nations International Children's Emergency Fund
<b>UNDIS</b>	United Nations Disability Inclusion Strategy
<b>UNPRPD</b>	United Nations Partnership on the Rights of Persons with disabilities
<b>UNV</b>	United Nations Volunteers
<b>WCAG</b>	Web Content Accessibility Guidelines
<b>WBU</b>	World Blind Union

<b>WFD</b>	World Federation of the Deaf
<b>WFDB</b>	World Federation of the Deafblind
<b>WHO</b>	World Health Organisation
<b>WNUSP</b>	World Network of Users and Survivors of Psychiatry

## Foreword by the President of IDA

The second IDA Global survey on Participation of Organizations of Persons with Disabilities comes in a year in which the world has been shaken by multiple crises but also a year that saw opportunities to advance the rights of persons with disabilities. We are in the third year of the COVID-19 pandemic and hopefully what it looks to be its last. This pandemic catastrophically and disproportionately impacted persons with disabilities. Simultaneously, the war in Ukraine once again reminded the disability rights movement that the world is not prepared to protect persons with disabilities in times of humanitarian crisis and conflict. Finally, increasing and looming financial crises around the world, coupled with the crisis of multilateralism and globalization, threaten to undermine successes of the disability rights movement that were slowly and steadily secured over many years.

On the other hand, the [Global Disability Summit](#) that was held in February 2022 introduced optimism and repositioned disability rights as a priority of the world leaders once again. [Wethe15 campaign](#) is another source of optimism with its unprecedented successes and perhaps the beginning of a paradigm shift in reframing the disability narrative around the world.

Against this turbulent background, and in a fast-changing global background, IDA implemented the [second Global survey on Participation of Organizations of Persons with Disabilities](#). It is now more important than ever to understand how organizations of persons with disabilities take part in decision-making processes with their governments and international development stakeholders. We believe, we know that **there cannot be sustainable development without inclusion of persons with disabilities and their representative organizations in all decision-making processes**. That's why we are calling for transformation of our motto to simply, **nothing without us**, because indeed no policies, and no decisions should be implemented without the voices of persons with disabilities. The survey is capturing how organizations are seeing their role in decision-making and de facto invites stakeholders to do more and create preconditions for meaningful inclusion of persons with disabilities.

**We learned from the second survey that there is a slow and steady increase of OPD influence**, but continuation and increased dissatisfaction with their involvement with governments. This may suggest that OPDs are more aware of their rights and more equipped to demand payment of those rights from the government, while governments are not delivering on these expectations. Simultaneously, we noted that OPDs are increasingly satisfied with their involvement with international development stakeholders. This may suggest that international partners are increasingly welcoming organizations of persons with disabilities in their work, but also can speak about the power imbalance between OPDs and international partners – simply put, is it possible that OPDs are satisfied with any kind of involvement with international partners. **We remain concerned that preconditions for participation such as reasonable accommodation is perceived to have deteriorated overall**, as well as we learned that many groups of persons with disabilities are still left behind in decision-making. Unsurprisingly, we learned that COVID-19 pandemic disproportionately impacted the work of OPDs. Above all, it is clear from the survey that more investment is needed in OPDs capacities to meaningfully engage.

IDA would like to call for a transformational shift in understanding of OPD participation through ensuring meaningful participation in every step of the process, from the design stages onward. To achieve this transformational shift, **investments need to be accelerated in support services that enable participation, systematic accessibility and provision of reasonable accommodation need to be ensured, and participation of the diversity of persons with disabilities needs to be proactively planned and supported.** OPDs have a lot of experience and expertise and we are calling for investment in building capacities of organizations of persons with disabilities as well as in creating processes to learn from technical capacities of OPDs. Finally, to achieve all of this, OPDs need to have higher access to funding and opportunities to develop their organizations.

Consultations, decision-making process and any projects and initiatives implemented by governments or international partners cannot achieve sustainability or real change without meaningful, inclusive, and accessible participation of persons with disabilities. **It is now more important than ever to invest in building capacities of organizations of persons with disabilities while simultaneously committing to transformational change in inclusion of persons with disabilities in all decision-making process.**

*Yannis Vardakastanis, President of the International Disability Alliance (IDA)*

# Acknowledgements

IDA wishes to warmly thank all representatives of organisations of persons with disabilities (OPDs), IDA members, their members and beyond, who took interest and dedicated their time to respond to this survey. This report provides a collective picture, based on the insights and perspectives they provided.

Our recognition and appreciation also go to their tireless efforts, as OPDs, to advance the rights of persons with disabilities by representing their unique views and ensuring they inform participatory and inclusive decision-making processes.

The analysis of the data collected through the first IDA Global Survey was done in partnership with the Assistive Living and Learning (ALL) Institute, Maynooth University, Ireland. IDA is particularly thankful to Rebecca Daniel, Prof. Malcolm MacLachlan and Prof. Delia Ferri for their technical assistance in the production of this report.

IDA also wishes to thank IDA members who contributed to working groups which led to a more inclusive and accessible second IDA Global Survey, including representatives from the African Disability Forum (ADF), Down Syndrome International (DSI), the European Disability Forum (EDF), Inclusion International (II), the Latin American Network of Persons with disabilities and their Families (RIADIS), the World Blind Union (WBU), the World Federation of the Deaf (WFD), the World Federation of the Deafblind (WFDB), and the World Network of Users and Survivors of Psychiatry (WNUSP).

Finally, IDA extends its gratitude to the Ministry for Foreign Affairs of Finland, the Foreign Commonwealth and Development Office (FCDO) of the United Kingdom, the Inclusive Futures programme, the Swiss Development Cooperation, CBM, the Department of Foreign Affairs and Trade of Australia (DFAT) and the Swedish International Development Cooperation Agency (Sida) for their financial support to this work. The content of this report is the responsibility of IDA and its contributing partners and does not necessarily reflect the views of donors.



# Executive Summary

## Background

### Participation of OPDs is essential to leave no one behind

Participation of citizens is a human right, and a fundamental principle for democratic societies, good governance, and social accountability. Developed as a unique human rights instrument to address entrenched discrimination towards persons with disabilities, the UN Convention on the Rights of Persons with Disabilities (CRPD) centrally promotes participation of persons with disabilities, as a desired outcome and a process to achieve that outcome. **The CRPD uniquely stresses the importance of Organisations of Persons with Disabilities (OPDs) and their role as intermediary bodies to represent persons with disabilities in decision-making processes.** Increasingly, prominent global agendas such as the 2030 Agenda for Sustainable Development call on decision-makers to address persisting inequalities experienced by persons with disabilities with core messages to leave no one, including no person with disabilities, behind.

### Nothing without us?

However, as regularly flagged by the CRPD Committee, participation of OPDs in decision making remains largely insufficient. **Stigma and negative attitudes, legal barriers, economic obstacles, physical barriers, and informational or communicational barriers prevent participation of OPDs on an equal basis with others.** This perpetuates exclusion of persons with disabilities from all areas of society, as policies and programmes are built without their views, and are not responsive, not effective or worse, continue to hinder the rights of 15% of the world's population. Despite significant progress and commitments to disability-inclusive development and humanitarian action, the experience of IDA as a global alliance of OPDs is that pledges are not yet turned into action, and do not systematically ensure participation of OPDs as right-holders. With this comes the risk of disability being merely a box to tick, and participation of OPDs being tokenistic.

### Monitoring participation of persons with disabilities through their representative organizations

In 2018, IDA and its members developed a Global Survey on OPD participation to take the pulse of OPDs' own perceptions of their participation with government and international partners. Results of the first IDA Global Survey were published in early 2019. The survey was part of a strategy for holding decision makers on local, national, regional and international levels accountable for their commitment towards inclusion of people with disability and a tool for monitoring progress with Articles 4.3 and 32 of the CRPD. It provided a baseline to **analyse the quality, depth, scope and relevance of OPD participation in decision-making.** Evidence from the first survey demonstrated that, while OPDs were increasingly consulted, real participation was found to be lacking (IDA, 2020).

## OPD participation in a world shaken by multiple crises

Since the release of the first IDA Global Survey report, the world has changed significantly. Unprecedented global challenges have emerged including the COVID-19 pandemic, the environmental crisis, as well as multiple humanitarian crises, all being **new threats to civic participation and heightening barriers for OPDs participation**. On the more positive side, the launch of the United Nations Disability Inclusion Strategy (UNDIS) and its accountability framework has created requirements for the whole UN system to systematically consult with persons with disabilities. International cooperation partners have also taken **clear steps towards rights-based approaches to disability-inclusive development and humanitarian action**, such as through the commitments formulated during second Global Disability Summit.

## Monitoring evolutions overtime: from the first to the second IDA Global Survey

The second IDA Global Survey, launched in 2021, provides us with an opportunity to monitor evolution with OPD participation against a fast-changing global background. The second survey integrates learning from the first, in particular the need to improve accessibility of the online survey tool. Efforts were invested in accessibility of the online platform, including new technical functionalities developed with our members and tested by a range of persons with disabilities with diverse accessibility requirements. Proactive outreach to a diverse audience was also done through 21 webinars and workshop sessions in different languages. Thanks to this, **the pool of respondents is significantly greater and more diverse** than for the first survey, for example responses from persons with intellectual disabilities increased from 1,4% to 11,9%, and responses from persons with psychosocial disabilities from 2,6% to 7.3% of total respondents. A significant proportion of OPDs respondents reported involvement mainly at local level (43%) or national level (42,8%), and fewer at regional and international level (14,2%). Altogether, **1,341 individual respondents from across all regions, including respondents from 136 countries provided their views**.

## Key findings

*“This is the whole scenario - ambiguousness and that all. We have a lot for satisfaction, simultaneously a lot for dissatisfactions.” Respondent from Bangladesh*

The main message from the second Global Survey is that while participation is increasing in quantity, with more solicitations of OPDs on a wider range of issues, the quality of participation is not satisfactory for OPDs. In fact, OPDs report that their participation is far from being meaningful. As OPDs' influence is growing but their satisfaction with participation is not, it is important to go beyond an apparent paradox: more participation does not necessarily mean better participation.

More specifically, the survey data shows:

**1. A slow and steady increase of OPD influence, but overall dissatisfaction with their involvement with governments**

When asked about their level of influence on decision making as compared to one year ago, OPDs continue to report **increase with their capacity to influence international partners**, with over 55% saying their influence improved. However, this increased influence is not matched by greater satisfaction of OPDs regarding their engagement with their governments. **While 45,6% of OPDs were not pleased at all, or overall were displeased with their work with governments in 2018, this increased to 52,9% in 2021.** The apparent contradiction between more participation and less satisfaction suggests that OPDs may be more aware of what they are entitled to, more ambitious in their aims, or more equipped to claim voice and space for their cause. Therefore, they may be less satisfied with their current participation with government, despite making some progress. In contrast, **satisfaction with OPDs interaction with international partners has increased** from 37,5% reporting they were overall or totally pleased in 2018, to 46,3% giving these responses in 2021.

**2. OPDs are consulted on a wider range of issues, usually matching their priorities**

Progress is significant regarding the range of issues on which governments invite OPDs to participate. While in 2018, 81,70% OPDs reported being consulted exclusively on disability-specific issues, such as a disability law or policy, in 2021 this dropped to 31,5%. This reflects **wider mainstreaming of disability across different agendas, such as education or health.** This evolution is however not observed with international partners with a slight increase in OPDs reporting they are only consulted on disability-specific issues –most likely due to new international partners engaging for the first time on disability with a targeted approach. **Education, employment and health are clear priority issues of OPDs.** Comparison between issues prioritized by OPDs and issues on which OPDs are engaged by governments and international partners shows that OPDs are usually involved on issues that match their priorities, such as gender equality, access to healthcare, employment, and education.

**3. Participation remains limited in frequency and levels of shared decision-making, but is taking more formal ways**

Although slightly higher than in 2018, OPDs' levels of involvement in decision-making remain rather limited. **A majority of OPDs report that they are only invited occasionally to participate in work with governments or international partners.** Furthermore, they are less often involved in influential roles, especially when it comes to budget decisions (with 34,6% OPDs never invited to contribute on budgeting, and 26% on monitoring and evaluation). They are hardly ever associated as partners in co-deciding roles by either governments or international partners. While participation takes place through more formal mechanisms, such as through having a seat at a national disability council, this may not result in actual influence on decision-making. This persisting trend of low levels of engagement does not apply to the United Nations, whose capacity to

ensure preconditions for participation is perceived as stable or slowly increasing. This encouraging finding echoes the progress self-reported by the UN system against the objectives set by the UN Disability Inclusion Strategy (UNDIS), three years after its launch.

#### 4. **Many groups of persons with disabilities are still left behind in decision-making**

Groups who are more frequently involved in decision making are persons with physical impairments, deaf persons or persons who are blind or partially sighted. **Persons with deafblindness, persons with intellectual disabilities, persons with psychosocial disabilities and hard of hearing persons are involved to a much lesser extent.** Groups who are the least involved are persons affected by leprosy, persons with a chronic disease, persons of short stature, persons with epilepsy, albinism or vitiligo. As such, there is no evidence for greater involvement in decision making for many groups from the first to the second survey for many persons with disabilities.

#### 5. **Preconditions for participation, such as accessibility adjustments and reasonable accommodation, is perceived to have deteriorated overall**

In comparison to three years ago, when preconditions for participation were already not good, **OPDs perceive a greater setback in ensuring physical accessibility and informational-communicational accessibility** in 2021. Positive attitudes and knowledge of decision makers on what is required for meaningful OPD participation are perceived as significantly lower than in the first Global Survey. While 14% of respondents for the first survey reported that provision of funding for reasonable accommodation was not ensured at all, the percentage of respondents reporting this actually increased to 41% in 2021. As the scope of issues on which OPDs are consulted has broadened overall, it is likely that stakeholders engaging for the first time with OPDs are less familiar with the requirements of persons with disabilities to participate on an equal basis with others. The intention to include, but without experience of how to include, may create discriminatory consultation practices.

#### 6. **OPDs lack capacities, resources and opportunity to meaningfully engage**

Respondents explained that their organisations often lack experience and knowledge about decision-making processes. **OPDs often have too few activists to be influential with decision-makers in all areas where they need to intervene.** OPDs lack time, training and experience as well as financial and human resources to meaningfully engage. This is sometimes compounded by legal barriers to establish and register an organization. A negative circle that is difficult to break hence perpetuates their exclusion by depriving OPDs of opportunities to strengthen their capacity to participate. **Power dynamics at play, both within and beyond the disability rights movement, keep some groups away, as they are perceived to have lower capacity to influence decision makers.** There is often a lack of recognition for OPDs' expertise, and a concern that non-representative disability organizations and sometimes parents are still too often in leading roles or speak on behalf of OPDs instead of fostering more collaborative processes.

## 7. The COVID-19 pandemic disproportionately impacted persons with disabilities, and also impacted on work of OPDs

**The majority of OPDs reported that they experienced challenges due to the pandemic, which has also impacted their participation in decision-making processes, halted funding and created new challenges to participate in the digital world.** A few respondents cited positive changes such as new forms of virtual connections and activism, or new engagement in disability-inclusive emergency response. However, overall, it was found that the pandemic increased poverty of persons with disabilities or threatened their health, reducing capacities for activism. Opportunity costs identified through the first survey were exacerbated in times of crisis. As expressed by a respondent, “there is more work, but less funding.”

## Recommendations

The second IDA Global Survey on OPD participation, and the comparison it allows for the first time with data collected in 2018, shows some positive changes, but also a slow and unsteady path towards meaningful OPD participation. As OPDs’ influence is growing but their satisfaction is not, it is important to go beyond an apparent paradox: **more participation does not necessarily mean better participation.**

The COVID-19 pandemic and multiple crises affecting democracy and human rights also create less conducive contexts for civil society engagement. Moreover, **with an increased understanding of their human rights, OPDs have increased expectations** from their governments. These expectations are not being met and OPDs are becoming increasingly impatient with the lack of progress in collaboration and consultation – and de facto with progress in the implementation of their human rights. This most likely explains the decrease in satisfaction in OPDs working with their governments.

In contrast, OPDs are positive about being increasingly **approached by international partners, even if this collaboration is not always meaningful or balanced in terms of power.** This may be explained by the global momentum for disability inclusion, fostered by the Global Disability Summits and the UN Disability Inclusion Strategy, which opens new collaborations, where OPDs were previously overlooked as development and humanitarian action partners. A clear overall message from OPDs for governments and international partners is that there continues to be a **significant under-investment in ensuring the preconditions for OPD participation to be meaningful.** As the rationale for engaging with OPDs is stronger, the implications of this shift in practice are only starting to be understood. From ensuring accessibility to addressing unequal power dynamics within projects, from strategies to truly leave no one behind, to equipping OPDs to grow and thrive as representative organizations - more needs to be done to enact promises. Commitments need to be matched with investments in OPDs as key partners to turn these rights into actions. Recalling that meaningful participation should...

- **respect, value and consider the unique role and perspective of OPDs as representative organizations.**

- **enable their regular and effective engagement, by ensuring equal opportunities for all to contribute.**
- **seek the highest levels of shared decision-making on all issues that concerns all persons with disabilities,**

...this report highlights [6 key recommendations](#), which are equally relevant to governments and international partners:

### 1. **Ensure higher levels of OPD participation in decision making and give more weight to their contribution, from the design stages onward**

When invited to contribute, OPDs are too often invited to participate in programmes that have already been designed without their inputs and are being asked to mostly to support outreach and awareness activities. Instead, OPDs should be invited to take part in policy and program design from the outset. Rights-based, inclusive programming requires that they are not only informed or consulted, but also considered for partnership roles, with clear opportunities to frame and influence decisions. OPDs should be given clear roles matching their priorities. There should be more investment in their capacity, from advocacy to technical training. Accountability adds quality to participatory processes: opinions shared by OPDs should be given due weight, feedback should be provided on how their contributions were used, and feedback should be sought on how participation could be improved.

### 2. **Remove legal barriers to participation and accelerate investments in support services that enable participation**

Governments should remove legal barriers to the participation of persons with disabilities and repeal discriminatory laws and policies that prevent their equal recognition before the law and equal opportunities to participate. Accountability should be ensured through measures to enforce anti-discrimination in practice. Structural barriers such as lack of accessibility and lack of support services to enable participation and inclusion should be addressed. This may be done through accessibility law and policy and increased investment in developing services that provide the 'missing link' for persons with disabilities' participation, including human assistance, access to assistive technology, accessible transportation, or disability-inclusive social protection that effectively compensate for the extra costs incurred by persons with disability.

### 3. **Ensure systematic accessibility and provision of reasonable accommodation in all consultation facilities and processes**

Governments and international partners need to systematically ensure accessibility of all consultation facilities and processes for all persons with disabilities, including through reasonable accommodation. This includes choosing accessible venues or teleconference technologies, ensuring accessible information and communication about opportunities to participate, ensuring accessible information and communication during the consultation through captioning, national Sign Languages and understandable formats, and ensuring adequate time for preparation and engagement. Co-designing processes for consultation with OPDs can lead to more effective engagement and outreach.

#### 4. Support OPDs to access funding and opportunities to develop their organization

Participation of OPDs should be properly resourced, not only through covering the costs of accessibility and reasonable accommodations in consultations, but also by investing in OPDs to equalize their opportunity to engage and contribute as partners. Investing in OPDs should consider proportionate funding conditionalities (for example, adapting due diligence requirements to the size of organization), accessible application procedures (for example in different several languages and formats) and capacity building in fundraising. OPDs should have access to adequate core funding and resources to support their existence, operations, organisational development, capacity to coordinate with their members and advocacy priorities and perform their role(s) with independence, autonomy and adequate capacity.

#### 5. Invest in and learn from OPDs' technical capacities

OPDs demand better support, to improve their organizational, technical capacities and leadership. This is particularly important for organizations of underrepresented groups and OPDs operating in rural areas. Participation in decision-making supports OPDs to learn and acquire the skills and agency to contribute more efficiently. Therefore, government and international partners should invest in a virtuous circle, whereby creating opportunities to learn and engage will result in higher-level contributions from OPDs. Capacity building in the area of international cooperation (for example, understanding of humanitarian response processes, project management, emerging issues such as climate change, etc.) also supports OPDs' relevance and efficiency as development partners. Furthermore, decision-makers should also learn from OPDs, not only as voicing the demand on behalf of persons with disabilities, but also as source of technical expertise and know-how on rights-based disability-inclusive responses.

#### 6. Proactively support participation of the diversity of constituencies, especially underrepresented groups

Leaving no one behind requires attention to all persons with disabilities, and proactive efforts to reach out to those furthest behind and overcome barriers that may prevent underrepresented groups of persons with disabilities from engaging. Persons with deafblindness, persons with intellectual disabilities, persons with psychosocial disabilities, persons with invisible disabilities such as being hard of hearing, and persons with disabilities facing intersecting forms of discrimination, such as women, children, youth, older and indigenous persons with disabilities require particular attention. Decision-makers should invest in OPDs as a movement, promoting unity (for example, respecting the leadership of a national cross-disability federation as the main national interlocutor) and diversity (for example, providing extra support to ensure active engagement of underrepresented groups). Indicators should be used to track progress and ensure accountability on meaningful inclusion of all. Participation and consultation modalities should be designed in ways that acknowledge and address power dynamics and seek to promote collaboration with cohesive cross-disability voice for greater impact.

# 1 Background and rationale

## 1.1 Why participation matters

### Participation is 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”<sup>1</sup>.

With the Convention on the Rights of Persons with Disabilities (CRPD), participation takes a new scope and dimension. 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 of persons with disabilities as a process supports the realization of the full and effective participation and inclusion in society as a desired outcome.** The CRPD recognizes that it is only by actively involving persons with disabilities themselves in decisions that concern them that such decisions can be relevant to them. Inclusive societies and communities can only be built through processes that include, consult and fully integrate the views and priorities of persons with disabilities.

### Participation of persons with disabilities through OPDs

Furthermore, the CRPD stresses the importance of organisations of persons with disabilities (OPDs) as representative organisations and a key vehicle to ensure participation of persons with disabilities. OPDs are a specific type of civil society organization and should be distinguished from others, such as organisation for persons

<sup>1</sup> 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) (UN 1996-2021, 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).

with disabilities. OPDs are those organisations that are led, directed and governed by persons with disabilities<sup>2</sup>, and bring a unique perspective to speak on their own behalf. Organisations of families of persons with disabilities are also considered OPDs (UN Committee on the Rights of Persons with Disabilities, 2018, para 12 d). The CRPD clearly establishes OPDs as intermediary bodies between policy makers and persons with disabilities (Cote, A, 2020). As such, OPDs are a key component of a diverse civil society and an important contributor to democracy.

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. As organizations of marginalized groups, OPDs have historically been excluded from opportunities to engage in decision-making, or as recognized development and humanitarian partners. It is therefore important to recognize the need to catch up and invest in strengthening the organizational, technical and governance capacities of OPDs to play their role as meaningful partners and counterparts.

## The added value of OPD engagement

OPD participation is not merely a moral imperative but it also 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 bene fit, with development programs improving their reach and effectiveness, and DPOs expanding their voice, gaining in luence 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.”*  
Australian Aid/DFAT, 2020

- **Creating ownership:** 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 calls for action which promotes a sense of ownership, acceptability and legitimacy among their members.
- **Enhancing accountability:** Internally, the recruitment of OPD members is defined by common goals that are defined and agreed upon by members. Externally, OPDs act as a watchdog and as part of civil society have a responsibility to monitor governments compliance with fundamental human rights standards.
- **Supporting empowerment:** Partnership is about meaningful dialogue, co-production and willingness to engage OPDs as trusted stakeholders and counterparts. This may lead to better advocacy outputs, identification of allies for coalitions, greater recognition of OPD contributions and further opportunities to participate.
- **Generating better outcomes:** OPDs collect and channel diverse views of their members,

<sup>2</sup> General Comment No.7 (UN Committee on the Rights of Persons with Disabilities, 2018), para. 11, page 4. 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.

thereby enhancing the chances that policies and programs are informed by and relevant to the differing priorities of this diversity. This can contribute to a positive impact and the relevance of decisions for a broader range of persons with disabilities.

## Participation needs to be meaningful

For participation to be impactful, it needs to be meaningful. The CRPD qualifies the nature of OPD engagement through numerous references to “**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 superficial attempts but that certain parameters must be met to ensure that persons with disabilities and their representative organizations are meaningfully and actively engaged.

There is no commonly acknowledged definition of meaningful participation of OPDs. The Committee on the Rights of Persons with Disabilities (2008, para 42-66) indicates in General Comment No.7 a number of obligations to States to guarantee effective and meaningful participation of persons with disabilities through OPDs. These sets of obligations can also be interpreted as **preconditions for meaningful participation**.

### Preconditions for meaningful participation as per CRPD General comment No. 7:

- 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;
- 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.

## 1.2 Why a Global Survey on OPD participation?

### Commitments to engage do not yet translate into participation

Despite the obligations set by the CRPD, and significant progress in including persons with disabilities in the global agenda, persons with disabilities are still widely excluded from decisions on matters that affect their lives. Since the adoption of the CRPD, major changes have been secured in how persons with disabilities are perceived, and new commitments have been made to include persons with disabilities, such as in the 2030 Agenda for Sustainable Development, the adoption of the UN Disability Inclusion Strategy, the Inter-Agency Standing Committee Guidelines on inclusion of persons with disabilities in humanitarian action, or the UN Security Council Resolution 2475 on inclusion of persons with disabilities in responses to armed conflict.

While this global momentum is very positive, **disability-inclusive commitments do not necessarily translate into a rights-based approach to disability inclusion that truly consults and engages with persons with disabilities**<sup>3</sup>. Persons with disabilities continue to encounter significant barriers to the exercise of their right to participate in public affairs (OHCHR, 2018). As stigma and power asymmetry have historically kept OPDs away from decision making, a risk remains that international Non-Governmental Organisations (INGOs), sometimes with good intention, speak on behalf of OPDs instead of fostering more collaborative processes<sup>4</sup>.

As an alliance of over 1,100 OPDs across 182 countries in the world, the International Disability Alliance (IDA) and its members have direct experience of barriers that continue to exclude persons with disabilities and their representative organizations from decision-making. Well-intended pledges too often result in financing actions and programmes that contravene or only partially uphold the CRPD and/or investments in strategies that perpetuate negative stereotyping and discrimination.

### Monitoring 'Nothing about us without us'

Against this background, IDA felt the acute need to collect broader evidence and analyse the reality of OPD's engagement in decision-making, and to monitor this regularly.

The first Global Survey on OPD participation was developed by IDA as part of a strategy for holding decision makers accountable for their commitments under Articles 4.3 and 32 of the CRPD. It was designed to take stock of the participation of OPDs in programmes and policies, by assessing their own perceptions of the quality, depth, scope and relevance of their participation. As such, it set a **baseline for monitoring further evolution of OPD participation over time**.

The IDA Global Survey on OPD participation is:

1. A tool to capture **OPDs' perceptions of their participation** with governments, the UN and funding agencies on a global scale
2. The **first global OPD-driven accountability exercise** to take the pulse of participatory practices as perceived by OPDs

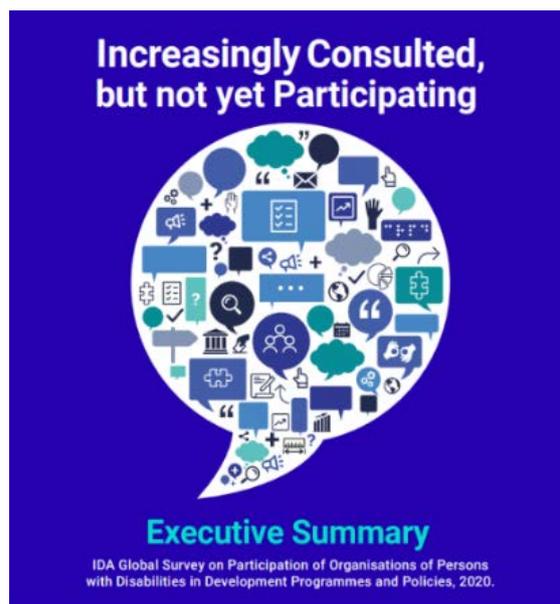
<sup>3</sup> In 2018, the CRPD stated that it "continues to observe an important gap between the goals and the spirit of articles 4 (3) and 33 (3) and the degree to which they have been implemented. This is due, among other things, to the absence of meaningful consultation with and involvement of persons with disabilities, through their representative organizations, in the development and implementation of policies and programs."

<sup>4</sup> UK aid (2021): [Consequences of Exclusion](#): A Situation Report on Organisations of People with Disabilities and COVID-19 in Bangladesh, Nigeria, and Zimbabwe. p. 28.

3. A **targeted monitoring tool** of the ‘Nothing about us without us’ motto, of Article 4.3 and 32 of the CRPD
4. **Generating more robust evidence and learning** on what works and what are the gaps to ensure ‘meaningful participation’
5. A contribution to **analyze different dimensions of meaningful participation**

### Findings from the 1st IDA Global Survey on OPD participation (2018-19)

The first IDA Global Survey collected views of over 570 OPDs from 165 countries. The main message from OPDs who responded is that **while OPDs are increasingly consulted, the scope and levels of participation remain insufficient**, and hampered (among others by a lack accessibility and reasonable accommodation and a wide range of financial, physical, attitudinal and knowledge barriers). Furthermore, views expressed by OPDs are not sufficiently considered, with involvement of OPDs often resulting only in tokenistic participation. The first Global Survey also showed that participation of persons with disabilities is not equal across the diverse constituencies of the disability rights movement, that OPDs are not consulted on all issues that concern them, but often only on disability-specific issues, and that satisfaction of OPDs with their involvement is much higher in their engagement with the UN than with other decision makers.



Please refer to the full report of the [first IDA Global Survey on OPD participation](#), and executive summary versions available in [English](#), [French](#), [Spanish](#), [Arabic](#), [Easyread format](#) and [International Sign Language](#).

### Use of the 1st IDA Global Survey to build the case for OPD participation

The first IDA Global Survey led IDA to set key parameters towards defining ‘meaningful participation’.

Meaningful participation is participation that:

- **Respects, values and considers the unique role and perspective of OPDs** as organisations representing the diversity of persons with disabilities,
- Enables their **regular and effective engagement**, by ensuring equal opportunities to contribute to decision-making
- 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

- **Secures the preconditions for participation**, including measures to equalize opportunities for persons with disabilities to contribute, through accessibility and the provision of reasonable accommodation.
- Acknowledges that **investment is needed to equip the diversity of OPDs with the resources to engage** (including technical, leadership, organisational skills).

### [Report of IDA 1st Global Survey on OPD](#)

#### [Participation](#)

The findings and recommendations from the first IDA Global Survey have been disseminated widely, and are used in IDA's continuous advocacy to build the case towards more meaningful engagement of OPDs in program and policy responses, including through international cooperation. For example:

- Evidence collected on OPDs' perceptions of their participation with the United Nations informed the development of the [UN Disability Inclusion Strategy \(UNDIS\)](#) and Indicator 5 of its accountability framework on consultation with persons with disabilities, as well as the [UNDIS Guidelines on Consulting with Persons with Disabilities](#).
- This work also supported efforts to prioritize a reflection on capacity building of OPDs through the **Global Action on Disability (GLAD) network**, and upcoming GLAD country case studies to understand how donors can best invest in OPD capacity building at the national level.
- OPD engagement was established as an overarching theme of the 2nd Global Disability Summit (GDS) with a dedicated menu of commitments. A [GDS Discussion Paper on](#)

[OPD engagement](#) was also produced and the call for case studies received unexpectedly strong interest, with over 90 submissions from a diversity of INGOs, donor, government and OPD representatives. **One in five of the commitments secured at the 2nd GDS in 2022 are related to OPD engagement.**

- Findings have also been used by national disability activists to build the case for more and better consultations with OPDs. At the regional level, the African Disability Forum (ADF) also performed an analysis of findings specific to Africa to support advocacy in the region.

*"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."  
"United Nations Disability Inclusion Strategy"*

### [Tracking evolutions: the context for the 2nd IDA Global Survey on OPD participation](#)

Participation is a complex alchemy and combination between the capacity of OPDs to articulate demands, invest in or claim space and the willingness and capacity of decision-makers to consult and effectively give consideration to their views. The wider political and socioeconomic context influences positively or negatively the participation of civil society in general. In other words, participation is a coproduction between OPDs, their willingness and readiness to engage, and decision-makers who have varying political will and capacity to consult and effectively include OPDs' views.

Since the first IDA **Global Survey was launched at the end of 2018, the world has changed considerably. Global challenges including the COVID-19 pandemic, the environmental crisis, multiple humanitarian crises, disinformation, increasing nationalism and populism challenging democratic values and the rule of law - all bring new threats to civic participation and heighten barriers for OPDs participation** (Inclusive Futures, 2021). These crises act as amplifiers of pre-existing inequalities and, once again, persons with disabilities are disproportionately affected. As their members, staffs, volunteers with disabilities are affected, OPDs are also affected.

For example, OPDs experienced dramatic reductions to funding and operational capacity during the COVID-19 pandemic, which had serious financial and psychological impacts on OPD staff and volunteers. OPDs' priorities are significantly impacted: "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" (Inclusive Futures, 2021, p. 11).

The 2nd IDA Global Survey, launched in 2021, provides us with an opportunity to monitor the evolution of OPD participation against this fast-changing global background.

## 2

# About the second IDA Global Survey on OPD Participation

## 2.1 Scope of the IDA Global Survey on OPD Participation

The Global Survey assesses the perceptions of OPDs themselves of the quality, depth, scope and relevance of their participation with governments (on local, national and regional level), UN Entities and funding agencies. It analyses **different dimensions of OPD participation**:

- **Who:** which groups of persons with disabilities are invited to participate?
- **With whom:** which decision-makers engage with persons with disabilities?
- **Where:** at which levels?
- **On what:** what are the issues on which OPDs are consulted?
- **How:** are preconditions for participation ensured?
- **When:** at which stages of the policy or program cycle are OPDs consulted?
- **How often:** is participation regular or occasional?
- **How formalized:** are mechanisms for participation formal or informal?
- **How much:** what is the level shared decision-making (from information to full co-decision)?
- **How effective:** are the views of OPDs effectively considered?

The IDA Global Survey does not target participation with specific partners or consultation mechanisms but aims to capture the diversity of ways and stakeholders with whom OPDs may engage. These include but are not limited to:

- Legal and regulatory frameworks and procedures across all levels and branches of government,
- Policies and strategies including national SDG plans, poverty reduction strategies, or sectoral policies in education, health, justice, etc.
- Programs of action and projects supporting the realization of policies and strategies
- The application of the above in all areas: disability-specific and non-disability specific policies and programs
- Policies and programs at local, national and regional levels (including implementation of global policies and programs at these levels
- Formal and informal ways of consulting and engaging with civil society in decisions-making.

### From the first to the second Global Survey: main lessons and adjustments

The first Global Survey, launched in December 2018, was the first online multilingual survey on OPD participation of that magnitude. This pilot experience generated learning which was integrated in the preparation of the 2nd Global Survey, launched in June 2021.

Adjustments were made to reduce barriers to participation and increase the quality of data collection in comparison to the 1st Global Survey, **while not losing comparability between the two survey versions**. While the first survey was one of the most accessible online surveys of that magnitude, digital barriers remained very high for many persons with disabilities. With the shift to online work accelerated by the global COVID-19 pandemic, efforts to develop an accessible online

survey platform tool was seen by IDA as a critical investment to bridge this disconcerting digital divide, both for and beyond the requirements of this survey (see below).

Below is a summary of the **main lessons learned** from the 1st Survey and how they were addressed in the 2nd iteration of the same Survey:

MAIN LESSONS LEARNED FROM THE 1ST SURVEY	RESPONSES AND ADJUSTMENTS 2ND SURVEY
<p><b>Respondents:</b> Respondents were limited to one person by OPD, influencing who responds and reducing the number and diversity of responses. The 1st survey collected 573 responses from OPD activists across 165 countries.</p>	<p><b>Respondents:</b> Responses were open to all persons with disabilities for the first few questions, and the extended questionnaire was sent only to those reporting engagement with an OPD, without limitation of the number of respondents per OPD. The 2nd survey collected 1,341 responses from across 136 countries.</p>
<p><b>Outreach:</b> The survey was widely disseminated in the 7 UN official languages and International Sign, through email and social media, as well as 21 webinars and in-person workshops which may have reduced access to people less involved in online communication.</p>	<p><b>Outreach:</b> With the extra challenges caused by the COVID-19 pandemic, including online survey fatigue, dissemination efforts were doubled including hosting of the survey in 9<sup>5</sup> languages and International Sign on IDA members' websites, 21 webinars and in-person workshops in 10<sup>6</sup> different languages and integration of sessions on the survey during IDA workshops and events. The chosen online survey tool (iData) is adapted to low connectivity environments with no data loss when losing connection.</p>
<p><b>Questionnaire:</b> The questionnaire was very long as the survey explored a wide range of situations. Responses suggest that OPDs did not distinguish clearly between the UN and funding agencies.</p>	<p><b>Questionnaire:</b> The questionnaire was shortened, some open-ended questions were altered to closed questions, skip functions were introduced to further reduce the length, the structure was strengthened, new questions were introduced, or wording was improved and made consistent. UN and funding agencies were grouped under a single category of 'international cooperation partners.'</p> <p>The online survey tool (iData) includes clearer navigation and highly flexible options to tailor questions to the profile of respondents (survey logic).</p>

5 Arabic, Chinese, English, French, Hindi, German, Russian, Spanish and International Sign

6 English, French, Spanish, Russian, Swahili, Uzbek, Arabic, Bengali, German and International Sign

<p><b>Accessibility:</b> Despite testing and choice of the most accessible online survey platform, respondents faced issues with navigation (structure of the survey) and had reduced options of alternative formats to access the survey (e.g., contrast change, read aloud, size).</p>	<p><b>Accessibility:</b> IDA launched a procurement to identify possible options for a more accessible tool and worked with Pre-Ignition to recommend and test missing accessibility options. 'iData' was developed with a unique functionality to adapt the parameters of the survey to the preferences of respondents, and offer new formats (read aloud, Easyread, etc.)</p>
<p><b>Accessibility:</b> The survey questionnaire was converted into plain language in partnership with Inclusion International who mobilized self-advocates to provide feedback. However, the questionnaire remained long, with no technical possibility to include a glossary nor have an Easy-read version.</p>	<p><b>Accessibility:</b> IDA worked with Inclusion International and Down Syndrome International to review the questionnaire with self-advocates, as well as to guide and test with the development the Easyread version of the online survey tool (iData). A webinar to launch the Easyread version included a demo of the tool by self-advocates to other self-advocates.</p>
<p><b>Technical issues:</b> The survey was translated into the 7 official UN languages however the online survey tool did not allow compilation into a single dataset, causing complications for data cleaning. Limited options for tracking responses while the survey was open reduced the ability to target dissemination efforts to missing groups or regions.</p>	<p><b>Technical issues:</b> The selected online survey tool (iData) allowed for the survey platform and questionnaire to be available in multiple languages, and responses to the multiple language versions to be aggregated into a single dataset. Technical issues – The selected online survey tool (iData) allowed for the survey platform and questionnaire to be available in multiple languages, and responses to the multiple language versions to be aggregated into a single dataset. The iData real-time analytics allowed for monitoring response rates and targeting dissemination efforts towards missing constituencies.</p>

## Survey languages and dissemination

The 2nd IDA Global Survey was made available in **9 languages**, including the 6 UN official languages (English, French, Spanish, Arabic, Chinese and Russian), International Sign, as well as Hindi and German.

The survey disseminated globally to reach worldwide geographical coverage. The survey was presented during 21 webinars and in-person workshop sessions coordinated by IDA and IDA members and workshops with OPDs in over 9<sup>7</sup> different languages; 7 workshops of external stakeholders; and mentioned during the opening of the 2021 Conference of States Parties (COSP14), the opening of the August 2021 session of the Committee on the Rights of Persons with Disabilities, and during the 2021 World Data Forum. A multi-language social media kit was produced, and promotional messages were disseminated widely through IDA's members, listservs, WhatsApp groups, social media, and [websites](#).

While responses to the 1st Global Survey were received overwhelmingly in English (71,6%), **efforts to disseminate the survey to a wide and diverse audience resulted in a better distribution, with English (49,3%) and Spanish (36%).** The Chinese version was only used by very few participants, related to barriers in sending individual data to outside of China. Similar issues to access of the survey were experienced by people trying to connect from Cuba.

**Figure 1– Number of respondents by survey language version 2021**

Number of respondents by survey language version - 2021	%
English	49,3
Spanish	36,0
French	5,4
German	3,9
Arabic	3,0
Russian	1,4
Hindi	0,7
Chinese	0,3
International Sign <sup>8</sup>	NA
<b>Total</b>	<b>100</b>

## 2.2 Survey accessibility: tools and functions guided, tested and improved with persons with disabilities

*"It's your opportunity, it's your survey, you have the right to choose how to take it" A self-advocate about iData during the launch webinar of the IDA Global Survey in EasyRead format*

Addressing accessibility barriers faced with the first Global Survey led IDA and its members to invest in the identification, adaptation, testing and use of a new tool for accessible online surveys.

<sup>7</sup> English, French, Spanish, Russian, Swahili, Uzbek, Arabic, Bengali, German and International Sign

<sup>8</sup> To be noted: Sign language is both a language and an accessibility requirement for Deaf persons, Hard of hearing persons and/or persons with deafblindness who use sign language(s). On the iData survey platform, respondents have an option to activate a version of the survey with International Sign video as part of accessibility options. For example, A participant based in France may choose to respond to the survey in French and activate the video in International Sign. Therefore, it is not possible to report on the number of respondents who used International Sign.

After exploring diverse options and launching an open procurement, IDA chose to partner and support the upgrading and testing of an existing online survey tool (developed by Prelgnition) and make it fully accessible. **iData** is the name of IDA's space and license for this accessible online survey platform.

## Investing in an accessible online survey tool: process and results

### A participatory process guided by persons with disabilities

1. Working Group on inclusive and accessible data collection created with 10 IDA members<sup>19</sup> to provide technical guidance and to discuss the collective experiences, priorities, mobilizing OPDs for dissemination, and recommend alternative and preferred options
2. Bi-lateral consultations with Inclusion International, Down Syndrome International, World Federation of the Deaf, and the World Blind Union to identify specific accessibility requirements and recommendations to improve accessibility and inclusion for their constituencies
3. Global Survey group formed with OPD representatives in Uganda to provide consultation with persons with disabilities from a sample Global South context, including low connectivity issues, led by an IDA Global Survey Fellow
4. 79 people, including 84% persons with different disabilities<sup>210</sup>, 50% women and 40% from underrepresented groups tested the tool with different software, connectivity, languages and other accessibility requirements
5. 4 types of browsers were used for testing (multiple versions): Chrome, Mozilla Firefox, Safari, Microsoft Edge
6. 5 levels of devices were tested: Magnifier, JAWS, NVDA, Voice over, Zoom text
7. On desktops, laptops, mobile phones and tablets
8. 5 levels of testing (through multiple rounds): automated technical testing of each component, accessibility feature testing, integrated app testing of all components, content testing and language testing
9. EasyRead version: a feature was designed and tested through a process centered on participation and consultation with 7 self-advocates with intellectual disabilities (4 women), and included recommendations for embedding illustrations

---

9 Representing persons who are blind, persons with deafblindness, Deaf persons, hard of hearing persons, persons with psychosocial disabilities and persons with intellectual disabilities from all over the world, especially from Asia and the Pacific, Africa, and Latin America.

10 Persons with albinism 2, persons who are blind or partially sighted persons 19, persons with cerebral palsy 4, Deaf persons 4, persons with epilepsy 1, hard of hearing persons 4, persons with intellectual disabilities 10, persons with multiple disabilities 2, persons with physical disability 15, persons with psychosocial disability 4, persons of short stature 1, persons without a disability 13

## iData, a uniquely accessible online survey platform

1. Unique in its ability to adapt the survey format to the diverse preferences of respondents; iData values the diversity of respondents' preferences rather than considering it as a constraint
2. Targets the highest international standards for digital accessibility Web Content Accessibility Guidelines (WCAG) 2.1 level AAA (meets AA and approaches AAA)
3. Possibility to create an Easyread version including illustrations side by side with plain language text
4. Possibility to view questions in Sign Language through video format
5. Adjustable color themes, contrasts, font size
6. Read aloud: accessing questions in audio format, with different voice speed
7. On demand helper text: to explain complex words or provide guidance on how questions should be answered, without overwhelming the interface
8. Reduces survey fatigue allows users to save and revisit responses later, collects information to similar questions only once (for users creating an app profile), entails clear structure and advanced skip options
9. Optimized for use within low internet connectivity: automatic saving options and optimization of the functionalities within low bandwidth
10. Introductory and 'how to use' video for iData tested by self-advocates
11. Optimization of iData on different devices (mobile, tablet, desktop), and browsers
12. Dynamic real-time analytics to visualize responses (including through maps and charts and dashboards)
13. Advanced international features to handle multiple languages (including right to left) and automated translation

The result of combined strategies for wide dissemination and outreach, optimized accessibility and participatory development proved to be successful and resulted in a more diverse group of respondents to the 2nd IDA Global Survey, presented in more details in

the following section. In particular, there is a significant increase in the number of respondents with intellectual disabilities as compared to the previous survey, from 1,4% to 11,9%, and from persons with psychosocial disabilities, from 2,6% to 7.3% of total respondents.

Overall, the experience of respondents with the survey was very positive. The open-ended question to capture feedback on survey accessibility or content of the survey reported overall positive feedback particularly on being able to active features based on their accessibility needs. Some respondents complemented the high relevance of the topic and the importance the data will play for their organization. However, some respondents still felt that the survey was too lengthy and complex. Other suggestions for improvement included additional languages or guidance.

*“The [...] survey integrates all aspects of the issue [...]. Having access to this survey allowed us to express ourselves and make our modest contribution.” Respondent from Congo*

*“I think this survey is excellent to take into account the reality.” Respondent from Colombia*

*“It has been very accessible and applaud the team that designed it.” Respondent from Uganda*

## 2.3 Survey respondents and characteristics

### Numbers

**1,341 respondents** shared their views through the 2nd IDA Global Survey. 845, i.e., 63%, of these respondents, are from Organizations of Persons with Disabilities (OPDs), either members, staff or volunteers. The survey explicitly targeted persons with disabilities and OPDs, however as the survey focuses on OPD participation, only respondents who indicated that they connect with or work through an OPD received the larger set of questions.

In contrast to the first Global Survey from 2018 (which had 573) responses, the second Global Survey explicitly motivated OPDs to select as

many respondents per organization as they wish. This – in combination with additional outreach efforts – led to a much higher number of responses than in the first survey. Recognizing that different people within the same OPD may have different roles and focus within their work with different decision makers, this approach seemed appropriate to get a greater diversity of views.

### Impairment of respondents

Amongst the total survey respondents 72,7% (i.e., 987) indicated that they identify as a person with a disability, while 24% said that they don't and 3% preferred not to say. The highest number of respondents with disabilities among all respondents are persons with physical disabilities, persons with intellectual disabilities, persons who are blind or partially sighted, persons with psychosocial disabilities, deaf persons as well as persons who are hard of hearing or have other hearing difficulties.

**A significant increase of the number of respondents with intellectual and psychosocial disability is notable in comparison to the first Global Survey.** There is also slightly more persons with autism and persons who are blind or partially sighted, or with deaf-blindness in the second Global Survey.

30% of the participants, furthermore, indicated that they needed support to participate in the survey, such as e.g., an assistant person or interpreter.

**Figure 2 – Distribution of survey respondents who self-identified as persons with disabilities by impairment group (in %), comparison between 1st and 2nd surveys**

<b>DISTRIBUTION OF SURVEY RESPONDENTS WHO SELF-IDENTIFIED AS PERSONS WITH DISABILITIES BY IMPAIRMENT GROUP (IN %), COMPARISON BETWEEN 1ST AND 2ND SURVEYS</b>	<b>2021</b>	<b>2018</b>
A person with physical impairments	28,9	29,8
A person with an intellectual disability	11,9	1,61 <sup>11</sup>
A person who is blind or partially sighted	9,7	9,3
A person with a psychosocial disability	7,3	2,6
A deaf person	6,9	8,3
A person who is hard of hearing or has other hearing impairments	5,2	5,5
A person with autism	2,0	1,2
A person with deafblindness	1,9	1,1
A person with multiple impairments	0,9	2,8
A person with a chronic disease	0,7	2,3
A person with short stature/ little people	0,7	0,5
A person with albinism	0,4	—
A person with cerebral palsy	0,4	—
A person with epilepsy	0,4	—
A person affected by leprosy	0,1	0,2
A person with vitiligo	0,1	—
Person with another impairment <sup>12</sup>	<b>1,3</b>	13,1

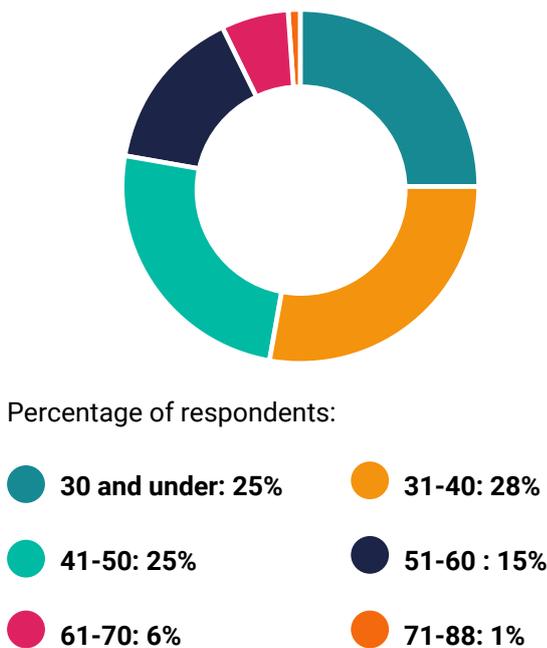
<sup>11</sup> The first global survey had separate categories of responses for intellectual disability (1,4%) and cognitive impairment (0,2%).

<sup>12</sup> Respondents who selected (other) specified their impairment: for example, neurodiversity such as dyslexia or dyspraxia as well as speech impairment, Tourette syndrome, or post-traumatic stress disorder

### Age, gender and other identity factors of respondents

**Age:** The average age of the respondents was **41 years**, which is slightly younger than in the first Global Survey (where it was 45 years)<sup>13</sup>. In the first Global Survey the restriction on only one respondent per OPD may have meant that more senior (and likely older) members of organizations were completing the survey; compared to the second Global Survey where the removal of this restriction may have meant that less senior (and therefore possibly younger) respondents were also completing the survey, thus reducing the average age of respondents.

**Figure 3 – Distribution of age groups of respondents, in %**

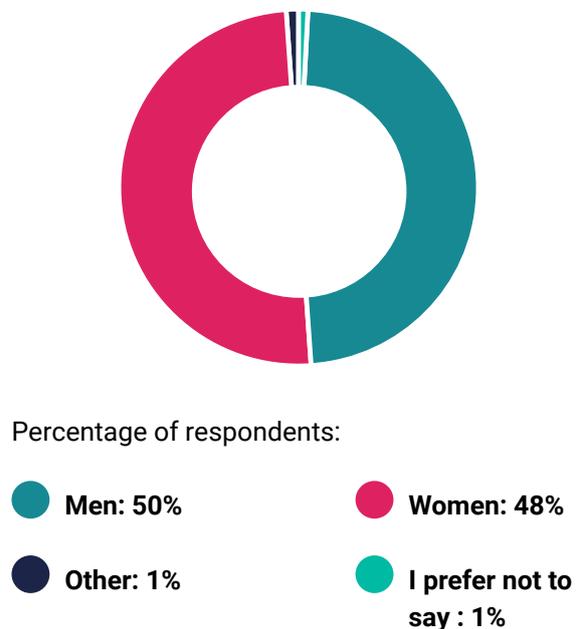


**Figure 4 – Distribution of age groups of respondents, in %**

DISTRIBUTION OF AGE GROUPS OF RESPONDENTS, IN %	2021	2018
30 under	24,9	14,7
31-40	27,8	24,0
41-50	25,0	25,7
51-60	14,7	22,4
61-70	6,4	9,0
71-88	1,1	4,2
89 and above	0,1	1,0

**Gender:** When it comes to the participants' gender a greater balance between self-reported males and females was apparent in the second Global Survey as compared to the first one, which the following overview shows.

**Figure 5 - Gender of respondent in %**



<sup>13</sup> Please note that the survey explicitly targeted adults, therefore 27 responses from respondents under the age of 18 were removed from the data set before analysis.

**Figure 6 – Gender of respondents, in %; comparison between 1st and 2nd surveys**

GENDER OF RESPONDENTS, IN %	2021	2018
Men	49,7	51,6
Women	48,4	47,4
Other	1,2	1,1

### Characteristics of responding OPDs

The following results are all from those respondents to the second Global Survey that are involved with an OPD (845). Respondents recorded below may be smaller than this where some respondents did not answer all questions and their responses of some items were therefore treated as missing data. With a wide range of OPDs who responded to the survey, representing a variety of disability constituencies, working at different levels and in different regions and countries of the world, the data set provides an interesting pool of informants. However, we do not claim to present results that are representative of other OPDs beyond this sample, and we do not attempt to extrapolate these results from the respondents to OPDs worldwide. We are also aware that even within countries where there was a good number of OPD respondents this number may still only represent a minority of people in OPDs in that country. Furthermore, it should be noted that due to the digital divide experienced by persons with disabilities, an online survey, even with strong accessibility features, has inherent limitations in terms of outreach to persons with no access to a device or internet.

### Level of work, countries and regions

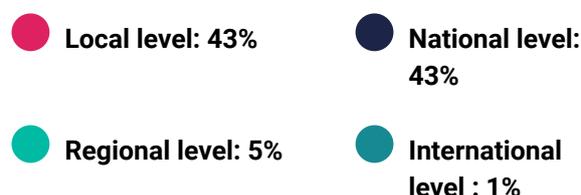
OPD respondents to the second Global Survey mainly work<sup>14</sup> at local and national level (85,8%),

with fewer working at regional or international level (14,2%). As compared to first survey, this represents a distribution with about 11% more local level OPDs participating in the survey. This may be due to diverse strategies for outreach to OPDs, including a tool adapted to low internet connectivity, and sessions organized for participants to complete the online survey questionnaire during in-person workshops.

**Figure 7 – Level at which OPDs mainly work, in %**



Percentage of respondents:



**Figure 8 – Level at which OPDs mainly work, in %**

LEVEL AT WHICH OPDS MAINLY WORK, IN %	2021
Local level	43,0
National level	42,8
Regional level	5,4
International level	8,9

<sup>14</sup> While the first Global Survey, where respondents could select as many countries as they like, in the 2021 iteration OPDs were asked to only indicate the country they mainly work in. This led to a slightly lower coverage of countries worldwide in comparison to the first Global Survey (136 as compared to 165 in the first survey). However, this was intended to help to contextualize the findings better by looking at the country context which the respondents are mainly referring to with their responses.

Asia, closely followed by Latin America and Africa were the regions which provided the largest number of survey respondents who work at local, national, or regional level. In comparison to the first Global Survey, the largest change in percentage of respondents is from Latin America (24,5% in 2021 compared to 4% in 2018). In contrast, responses from Europe dropped from 33% of the overall sample in 2018 to 10% in 2021). This may also reflect respective outreach efforts that were directed especially to OPDs from the Global South to capture more voices of those persons with disabilities, those left most behind.

Though the respondents to the second Global Survey were asked to select only one main region (or country) they work in, their response was occasionally counted double when a country belongs to two different regions (e.g., Middle East and North Africa and Europe).

**Figure 9 – Countries with highest number of respondents by % of sample and number**

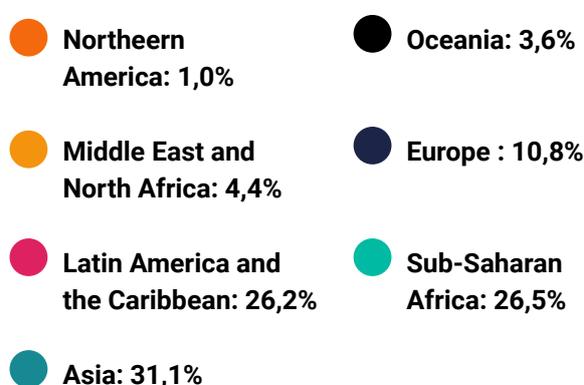
COUNTRIES WITH HIGHEST NUMBER OF RESPONDENTS	%	NUMBER
India	13,6	100
Bangladesh	10,5	77
Ecuador	6,4	47
Uganda	6,0	44
Kenya	5,3	39
Colombia	4,6	34
<b>TOTAL</b>	<b>46,3%<sup>15</sup></b>	<b>341</b>

<sup>15</sup> Proportion amongst all represented countries

**Figure 10 – Distribution of responses by regions, in %**



Percentage of respondents:



**Figure 11 – Distribution of responses by region, in % and number**

DISTRIBUTION OF RESPONSES BY REGION, IN % AND NUMBER	%	NUMBER
Asia	31,1	243
Sub-Saharan Africa	26,5	207
Latin America and the Caribbean	26,2	205
Europe	10,8	84
Middle East and North Africa (MENA)	4,4	34
Oceania	3,6	28
Northern America	1,8	14
Antarctica	0,1	1,0
<b>TOTAL RESPONSES</b>	<b>100</b>	<b>797</b>

## Groups represented

**Cross-disability organizations vs OPDs representing fewer constituencies** - Responding OPDs are quite diverse. 45% report being cross-disability organizations aiming to represent all persons with disabilities, such as national umbrella federations. 29% of OPDs report that they mostly represent one constituency of persons with disabilities, for example a local blind union. 21% say they represent more than one constituency, without however considering themselves cross-disability OPDs.

**Figure 12 – Groups represented by OPDs in %**



**Figure 13 – Groups represented by OPDs in %**

GROUPS REPRESENTED BY OPDS	%
OPDs mainly representing only one group of persons with disabilities	29
OPDs representing more than one group of persons with disabilities	21
OPDs working across disability and representing all persons with disabilities	45
Not sure	5,0
<b>Total responses</b>	<b>100</b>

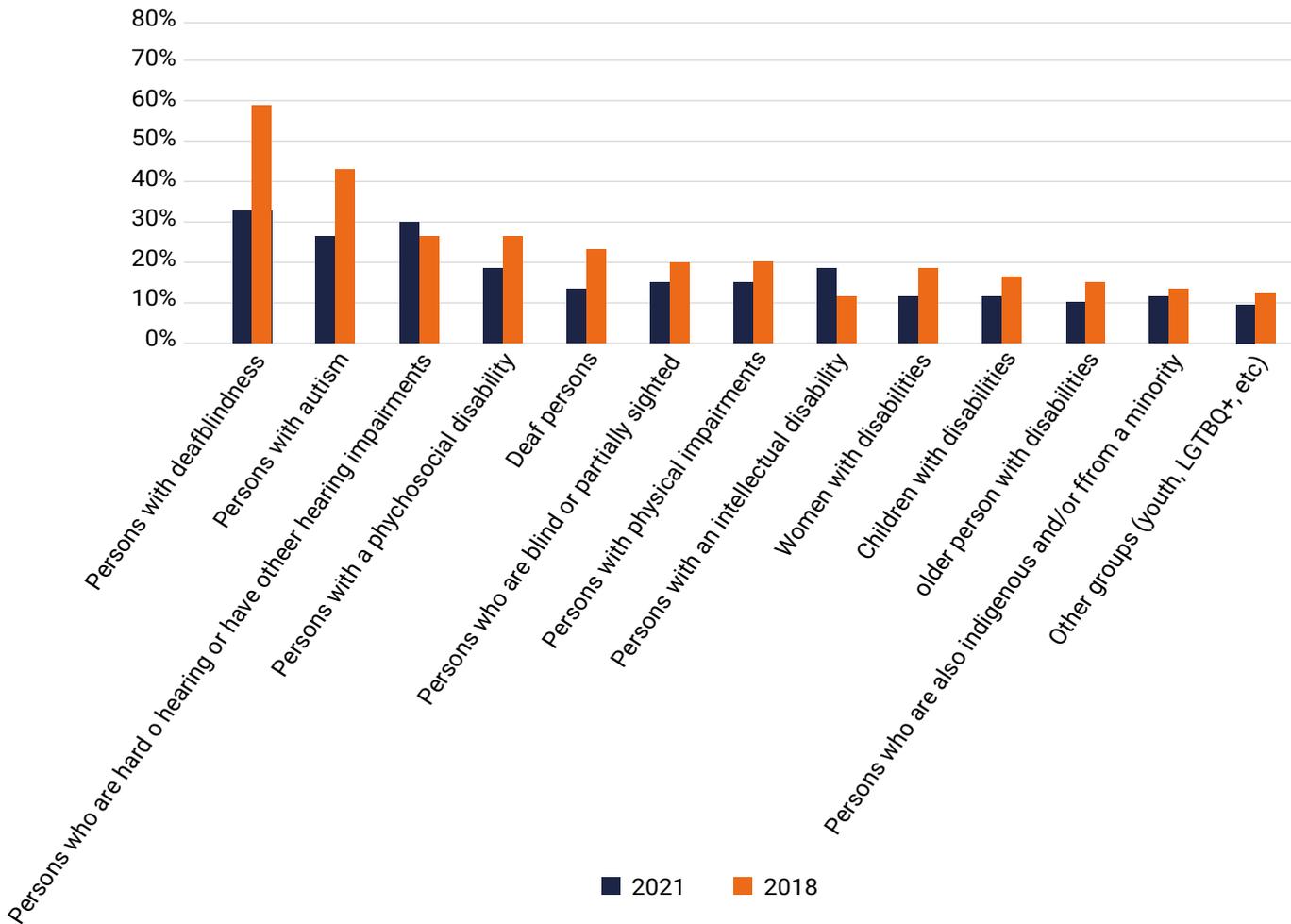
**Representation of other identity factors:** OPD respondents report they represent women with disabilities (66,4%), children with disabilities (58,6%), older persons with disabilities (56,4%), as well as indigenous groups of persons with disabilities and/or persons with disabilities from an ethnic minority (46,5%). Many fewer organizations reported representing youth (1,3%), persons with disabilities who are also LGBTQI+ (1,2%), or displaced persons (0,7%). This may be due to a variety of factors, including lack of attention to or identification of these identity factors by OPDs, lower engagement of these groups with OPDs due to higher levels of marginalization and/or fear for

their security, or discriminations from within OPDs towards these groups.

OPDs who report representing only one or a few groups of persons with disabilities are those representing mainly persons with intellectual disability (31,8%) or physical disability (30,2%), followed by persons who are blind or partially sighted (25,4%), persons who are deaf (23,8%), persons with a psychosocial disability (21,0%), persons hard of hearing or with other hearing impairments (20,3%), persons with autism (15,2%), and persons with deafblindness (14,3%). Other groups represented by OPD respondents included

persons with multiple impairments, cerebral palsy, albinism, or epilepsy, and persons of short stature. The below graphic and table represents this in more detail<sup>16</sup>. As compared with the first survey with over 37% of groups represented being persons with physical impairments, OPDs report a slightly more balanced representation of different groups of persons with disabilities.

**Figure 14 - Main groups of persons with disabilities represented by OPD respondents, in % comparison between 1st and 2nd surveys<sup>17</sup>**



16 Please note that one respondent could make more than one choice in case it's OPD is representing more than one group.

17 The difference in the number of responses under 'other' between 2018 and 2021 may be explained by a different online formatting of the question resulting in less respondents reporting 'other' groups.

**Figure 15 – Main groups of persons with disabilities represented by OPD respondents, in %; comparison between 1st and 2nd surveys**

<b>MAIN GROUPS OF PERSONS WITH DISABILITIES REPRESENTED BY OPD RESPONDENTS, IN %; COMPARISON BETWEEN 1ST AND 2ND SURVEYS</b>	<b>2021</b>	<b>2018</b>
Persons with deafblindness	<b>14,3%</b>	<b>17,5%</b>
Persons with autism	<b>15,2%</b>	<b>20,1%</b>
Persons who are hard of hearing or have other hearing impairments	<b>20,3%</b>	<b>26,4%</b>
Person with a psychosocial disability	<b>21%</b>	<b>18,5%</b>
Deaf persons	<b>23,8%</b>	<b>30,9%</b>
Persons who are blind or partially sighted	<b>25,4%</b>	<b>29,1%</b>
Persons with physical impairments	<b>30,2%</b>	<b>37,2%</b>
Persons with an intellectual disability	<b>31,8%</b>	<b>31,8%</b>
Women with disabilities	<b>66,4%</b>	<b>58,6%</b>
Children with disabilities	<b>58,6%</b>	<b>52%</b>
Older persons with disabilities	<b>56,4%</b>	<b>46,1%</b>
Persons who are also indigenous and/or from a minority	<b>46,5%</b>	<b>33,7%</b>
Other groups (youth, LGBTQ+ etc.)	<b>10,3%</b>	<b>75,7%</b>

## 3 Key findings

“This is the whole scenario - ambiguousness and that all. We have a lot for satisfaction, simultaneously a lot for dissatisfactions.”  
-respondent from Bangladesh

The main message from the second Global Survey is that while participation is increasing in quantity and opportunities, with more solicitations towards organizations of persons with disabilities (OPDs) on a wider range of issues, OPDs report that their participation is far from being meaningful. As OPDs' influence is growing their satisfaction is not. It is important to go beyond this apparent paradox: more participation does not mean better participation.

This chapter unpacks key findings from the survey to analyse and in doing so also highlights the risk of tokenism behind some modest but positive changes on OPD engagement.

### Summary of key findings from the second IDA Global Survey on OPD participation:

1. A slow and steady increase of OPDs influence, with satisfaction increasing on engagement with international partners, but decreasing on engagement with governments.
2. OPDs are consulted on a wider range of issues than before, usually matching their own priorities.
3. Participation remains limited in frequency and levels of shared decision-making, but is taking more formal pathways
4. Many groups of persons with disabilities are still left behind in decision-making.

5. Preconditions for participation, such as accessibility adjustments and reasonable accommodation, is perceived to have deteriorated overall.
6. OPDs continue to lack capacities, resources and opportunity to meaningfully engage.
7. The COVID-19 pandemic disproportionately impacted persons with disabilities, and also impacted on the work of OPDs.

### Finding 1 – A slow and steady increase of OPD influence, with satisfaction increasing on engagement with international partners, but decreasing on engagement with governments

#### In summary:

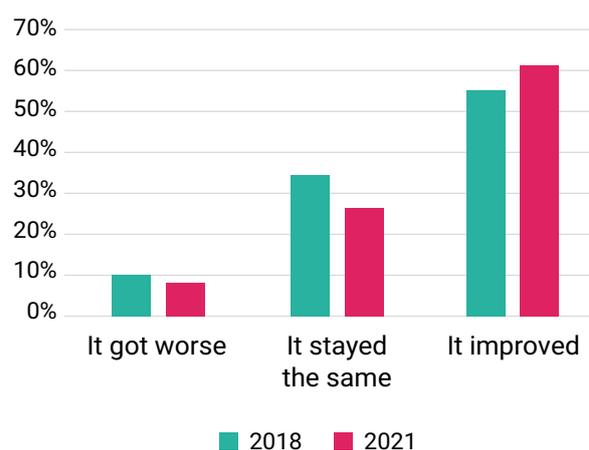
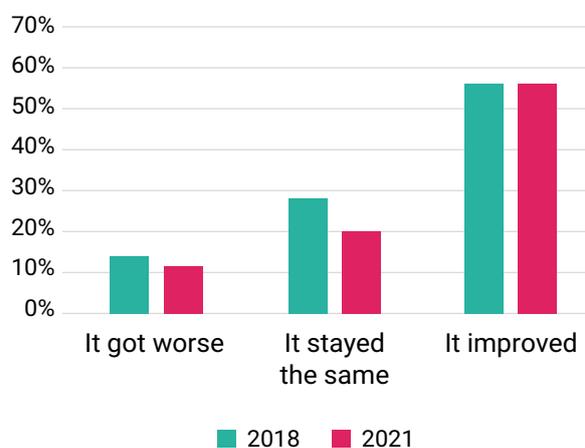
- When asked about their level of influence on decision making as compared to one year ago, OPDs continued to report having capacity to influence international partners, with over 55% saying their influence had improved.
- However, this increased influence with international partners is not matched by greater satisfaction of OPDs regarding their engagement with their own governments. While 45,6% of OPDs were not pleased at all, or overall were displeased with their work with governments in 2018, this increased to 52,9% in 2021.

- The apparent contradiction between more participation and less satisfaction suggests that OPDs may be more aware of what they are entitled to, more ambitious in their aims, or more equipped to claim voice and space for their cause. Therefore, they may be less satisfied with their current participation with government, despite making some progress.
- In contrast, satisfaction with OPDs interaction with international partners has increased from 37,5% reporting they were overall or totally pleased in 2018, to 46,3% giving these responses in 2021.
- A possible explanation is that thanks to the global momentum fostered by milestones such as the Global Disability Summit, the Inter-Agency Standing Committee Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action, or the UN Disability Inclusion Strategy, more international partners are newly engaging on disability issues. Progress is therefore more visible, with new access to opportunities of collaboration that did not exist before.

### OPDs report a slow but continuous improvement of their influence with decision-makers

A first positive finding from the survey is a perceived improvement in OPD influence. When asked about their level of influence on decision making as compared to one year ago, OPDs shared similar views to when they were asked to make this comparison three years earlier: they continue to report a steady and positive trend with their capacity to influence, with **over 55% saying their influence improved with governments and over 60% with international partners.**

**Figure 16 (a) and 16 (b) – Evolution of OPD influence with governments (a) and with international partners (b), comparison between 1st and 2nd surveys**



**Figure 17 – Evolution of OPD influence with different stakeholders, in %; comparison between 1st and 2nd surveys**

CHANGE OF INFLUENCE ON WORK WITH ALL ACTORS IN % 2018	GOVERNMENTS		INTERNATIONAL PARTNERS		REGIONAL INTEGRATION ORGANIZATIONS	
	2018	2021	2018	2021	2018	2021
It got worse	14,60%	13,1%	10,30%	7,7%	NA	9,7%
It stayed the same	29,20%	22,4%	34,25%	16,1%	NA	17,1%
It improved	56,20%	56,3%	55,45%	61,3%	NA	63,4%

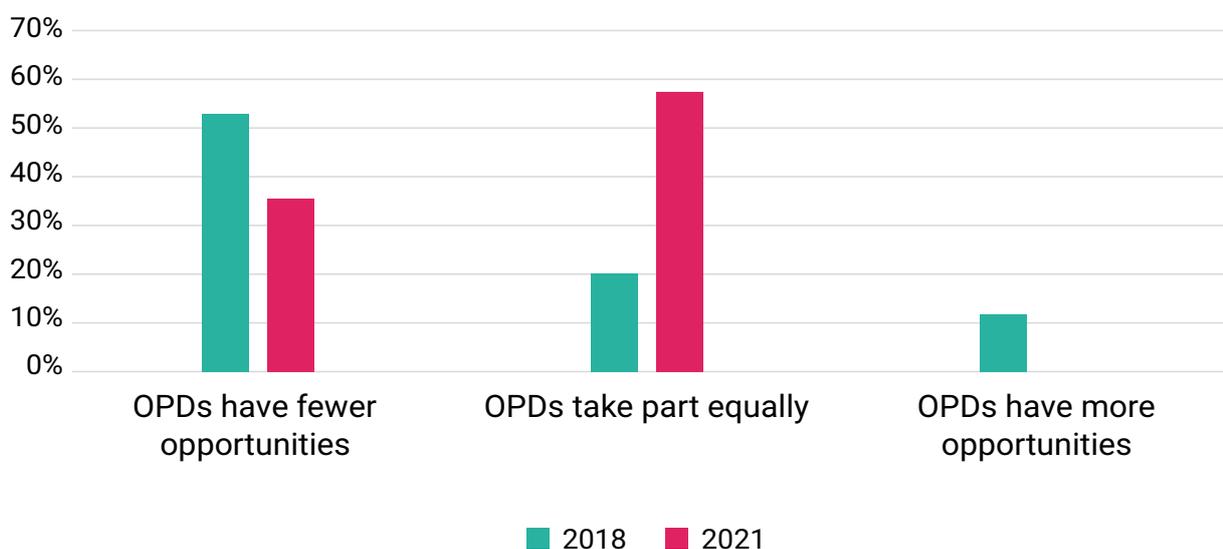
Most of OPDs report that they do have some impact on the work of all stakeholders. This includes engaging to claim civic space, for example: *“There is a lot more involvement of youth since after we complained about not being involved.”* (Respondent from Kenya about their work with governments).

### OPDs perceive that their opportunity to participate is becoming more equal to other civil society groups

OPD respondents were asked how they can participate in work with their governments, as

compared with other civil society groups. An interesting shift has taken place in comparison to 2018. While 54% thought they had less opportunities than other civil society groups in 2018, this number dropped to 35,2% in 2021. **A clear majority of OPD respondents perceive that they now take part in governmental decision making on a more equal basis with other civil society groups.** This suggests that the case for disability inclusion is stronger today, with more systematic consultations of representatives of persons with disabilities. As OPDs engage more, their appreciation of sharing space with other civil society groups’ seems more apparent.

**Figure 18 – Level of opportunities compared with other civil society, in %; comparison between 1st and 2nd surveys**



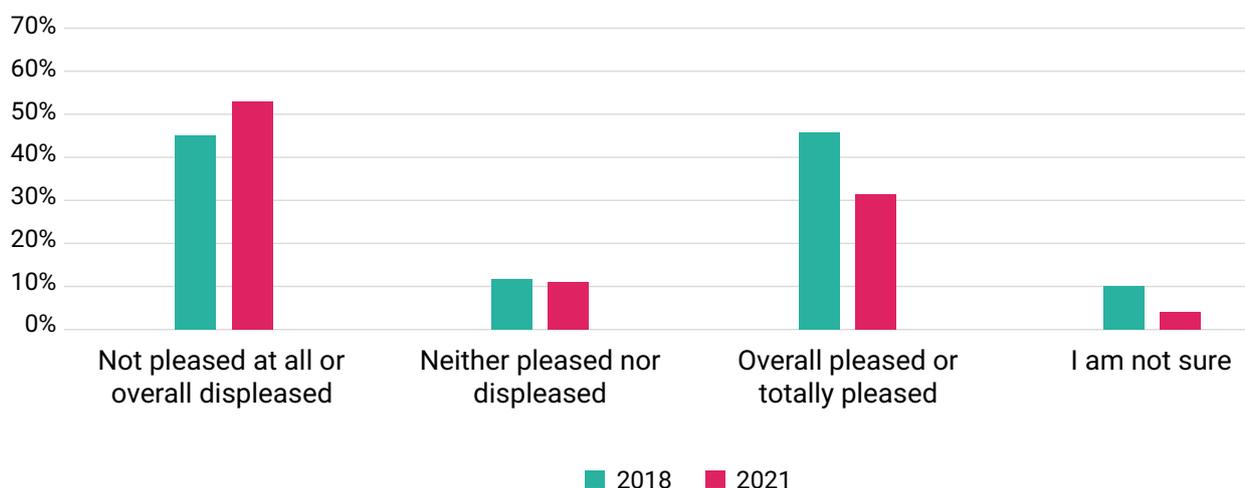
**Figure 19 – Level of opportunities compared with other civil society, in %; comparison between 1st and 2nd surveys**

OPD/ CSO PARTICIPATION COMPARED IN %	2018	2021
OPDs have fewer opportunities	54,0%	35,2%
OPDs take part equally	21,0%	56,7%
OPDs have more opportunities	12,0%	0,0%
I am not sure	13,0%	8,2%

### OPDs are not satisfied with their engagement with governments

Having more influence does not mean, however, that progress is perceived as sufficient or meaningful. Due to decades of discrimination, some OPDs often start their journey towards meaningful participation from a very low point, and a first degree of engagement is seen as progress from total exclusion in decision-making. Yet the pathway towards realizing meaningful participation as envisaged in CRPD Article 4.3 remains long and winding. This is reflected in **lower levels of satisfaction of OPDs regarding their engagement with governments: while 45,6% of OPDs were not pleased at all, or overall displeased with their work with governments in 2018, this increased to 51,6% in 2021.**

**Figure 20 – Evolution of OPD satisfaction with their engagement with governments, in %; comparison between 1st and 2nd surveys**



**Figure 21 – Evolution of OPD satisfaction with their engagement with governments, in %; comparison between 1st and 2nd surveys**

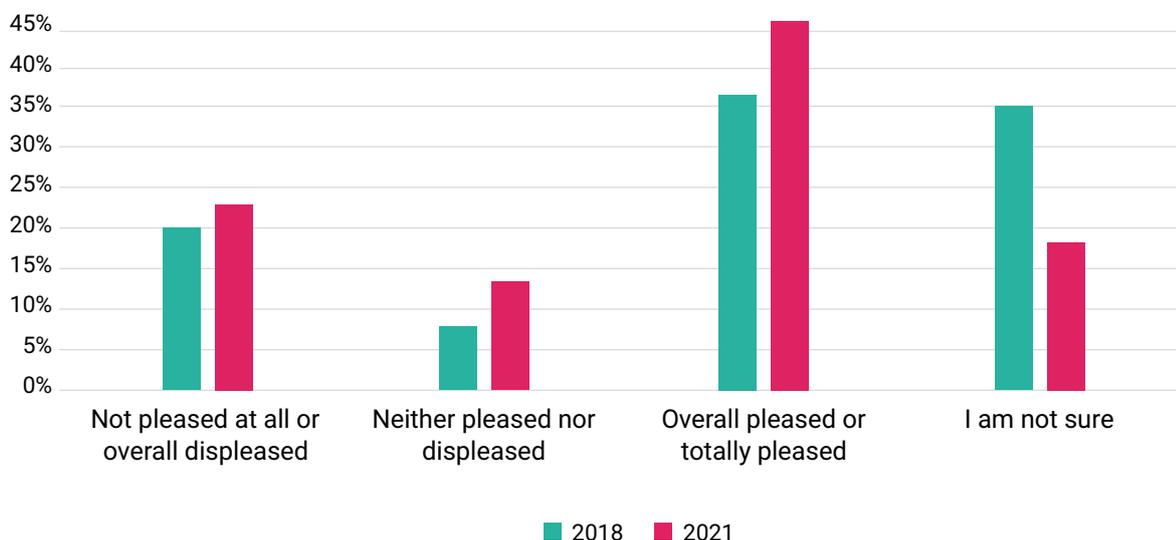
EVOLUTION OF OPD SATISFACTION WITH GOVERNMENTS, IN %	2018	2021
Not pleased at all or overall displeased	45,6%	51,6%
Neither pleased nor displeased	13,0%	12,5%
Overall pleased or totally pleased	45,6%	32,0%
I am not sure	10,4%	4,0%

The apparent contradiction between more participation and less satisfaction suggests that OPDs may be more aware of what they are entitled to, and more equipped to claim voice and space, but less satisfied with the outcome of their participation. As commented by a respondent from Tunisia, *“the consultation and participation of people with disabilities is not effective, it does not seem that the participation really has an impact on the decisions that already seem to be taken. In addition, it seems that the participation of DPOs only concerns subjects that are not disputed, whereas we should be consulted on subjects such as the budget allocated”*.

**OPDs are however more positive about their engagement with international partners**

On the other hand, as shown in figure 22 below, **satisfaction with international partners increased from 37,5% in 2018 to 46,3% in 2021**. A more positive attitude towards international partners is also reflected in the perceived influence of OPDs which is higher with international partners (figure 17 above). A possible explanation is that thanks to the global momentum fostered by milestones such as the Global Disability Summit, the Inter-Agency Standing Committee Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action, or the UN Disability Inclusion Strategy, more international partners are newly engaging on disability issues. Progress is therefore more visible, with new access to opportunities of collaboration that did not exist before. As stated by a respondent from Zimbabwe, *“intergovernmental organisations now starting to implement disability inclusion policies.”* In contrast to the international situation, OPDs usually have a longer history of engagement with local or national governments and so may be becoming increasingly impatient with the lack of progress in collaboration and consultation locally and nationally – and de facto with the progress with the implementation of their human rights.

**Figure 22 – Evolution of OPD satisfaction with their engagement with international partners, in %; comparison between 1st and 2nd surveys**



**Figure 23 – Evolution of OPD satisfaction with their engagement with international partners, in %; comparison between 1st and 2nd surveys**

EVOLUTION OF OPD SATISFACTION WITH THEIR ENGAGEMENT WITH INTERNATIONAL PARTNERS, IN %	2018	2021
Not pleased at all or overall displeased	19,8%	22,3%
Neither pleased nor displeased	7,9%	13,7%
Overall pleased or totally pleased	37,2%	46,3%
I am not sure	35,0%	17,7%

### Focus: engagement of OPDs with UN entities

*“Some UN agencies now seeing the value of involving our OPD in planning and designing their work.” Respondent from Zimbabwe*

The first Global Survey showed that OPDs were relatively distant from the United Nations, which they do not necessarily single out among international partners. This remains the case three years later, with almost a third (32,7%) indicating that they are not sure whether their OPD works with the UN or not. Those who are aware indicate that they mainly work with specific UN entities and processes as listed in the table below (Figure 24).

**Figure 24 – UN entities and process with whom OPDs engage, in %**

WORK WITH UN ENTITIES	%
United Nations International Children’s Emergency Fund (UNICEF)	26,3
The World Health Organisation (WHO)	24,5
The United Nations Development Programme (UNDP)	23,4
Projects from the United Nations Partnership to Promote the Rights of Persons with disabilities (UNPRPD)	21,5
UN Women	20,0
The Office of the High Commissioner on Human Rights (OHCHR)	19,9
The International Labour Organisation (ILO)	17,5
Training and awareness raising for UN staff on disability inclusion	13,6
Other UN Entities, UN working groups or programmes	9,8
UN Resident Coordinators Office	8,8
The United Nations Refugee Agency (UNHCR)	8,8
The Office for Coordination of Humanitarian Affairs (OCHA)	7,3
Development or review of common UN tools, such as Common Country Analysis, UN Development Cooperation Framework with the government, humanitarian clusters	5,7

The UN entities considered the most inclusive remain UNICEF and UNDP, which is consistent with the findings of the first survey.

**UNICEF** is reported to work a lot on inclusive

education and to also address disability inclusion well in other projects. Respondents also stress that UNICEF offers training for persons with disabilities and supports children with disabilities at the grassroots level and in rural areas. Some respondents mentioned that disability inclusion specialists work in UNICEF and that reasonable accommodation needs are usually considered in joint work with OPDs. Respondents also stress that UNICEF works a lot with OPDs and that they also support them to participate in

policy formulation activities at the government level. Its significant budget and wide range of programmes is considered essential to achieving its impact on the lives of children with disabilities. Some respondents stressed that UNICEF is one of the few UN Entities working with their OPD or in their country.

**UNDP** is, according to the respondents, an employer of many persons with disabilities who work on diverse programs, including some that are not targeting persons with disabilities. UNDP is seen by OPDs as working closely with governments and with rural and other communities, and as an agency that can impact on the lives of persons with disabilities (including children and women) in many areas (e.g., political rights, education, health, war and conflict). According to OPDs, UNDP addresses accessibility and offers support for persons with disabilities through its working relationships. Respondents also stressed that UNDP usually reaches out to consult OPDs regarding how its programs can become more inclusive and accessible.

**Figure 25 – UN entity considered the most inclusive by OPDs, in %**

WORK WITH UN ENTITIES	%
UNICEF	15,9
UNDP	15,9
UNPRPD	11,2
UN Women	9,3
WHO	8,9
OHCHR	8,4
UNFPA	4,7
ILO	3,3
UNESCO	3,3
UN Resident Coordinator's Office	3,3
UNHCR	2,8
UNV	0,9

## Finding 2 - OPDs are consulted on a wider range of issues than before, usually matching their own priorities

### In summary:

- Progress is significant regarding issues on which governments invite OPDs to participate. While in 2018, 81,70% OPDs reported being consulted exclusively on disability-specific issues, such as a disability law or policy, in 2021 this dropped to 31,5%. This reflects wider mainstreaming of disability across different agendas, such as education or health.

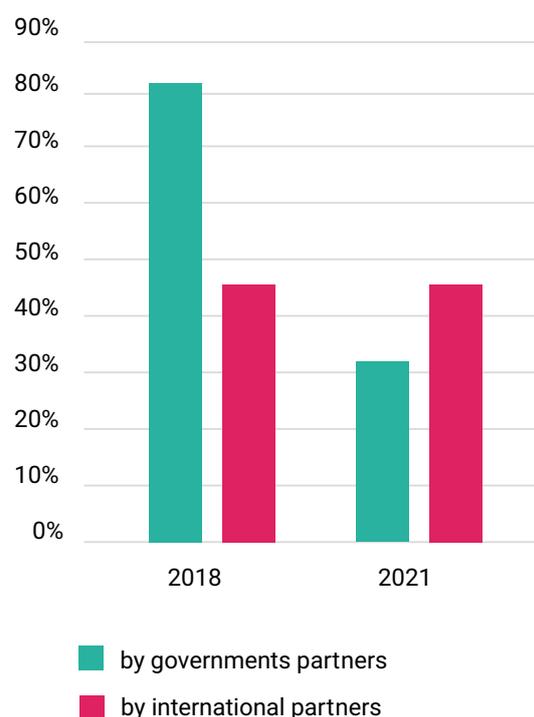
- This evolution is however not observed with international partners with a slight increase in OPDs reporting they are only consulted on disability-specific issues –most likely due to new international partners engaging for the first time on disability with a targeted approach.
- Education, employment and health are clear priority issues of OPDs, followed by gender equality, social protection, poverty reduction and access to justice
- Comparison between issues prioritized by OPDs and issues on which OPDs are engaged by governments and international partners shows that OPDs are usually involved on issues that match their priorities, such as gender equality, access to healthcare, employment, and education.
- The highest disconnects concern housing; social protection; culture, recreation and sports; employment; protection against violence; access to justice; as well as information and communication. This suggests that issues and services that are key enabling factors to persons with disabilities' participation and inclusion in their community are still insufficiently covered.

### There is significant evolution in the range of issues on which OPDs are consulted

Overall, fewer OPD respondents report being involved in decision-making related to disability-specific issues only, respectively 31,5% with governments, and 50,6% with international partners. This compares with 81,8% with governments and 43,6% with international partners (UN and donors) in the first global survey (2018), showing that overall, there is a **diversification of issues on which OPDs are consulted, showing progress with disability becoming part of the agenda**. It is interesting to note that compared with governments, international partners tend to consult OPDs

more exclusively on disability-specific issues, suggesting that disability is not yet 'mainstreamed' across their sectors of work but still considered a stand-alone topic (and perhaps explained by new actors engaging in disability for the first time, while governments deepen and diversify their way of engaging).

**Figure 26 – OPDs reporting they are consulted only on disability-specific issues, comparison between 1st and 2nd surveys**

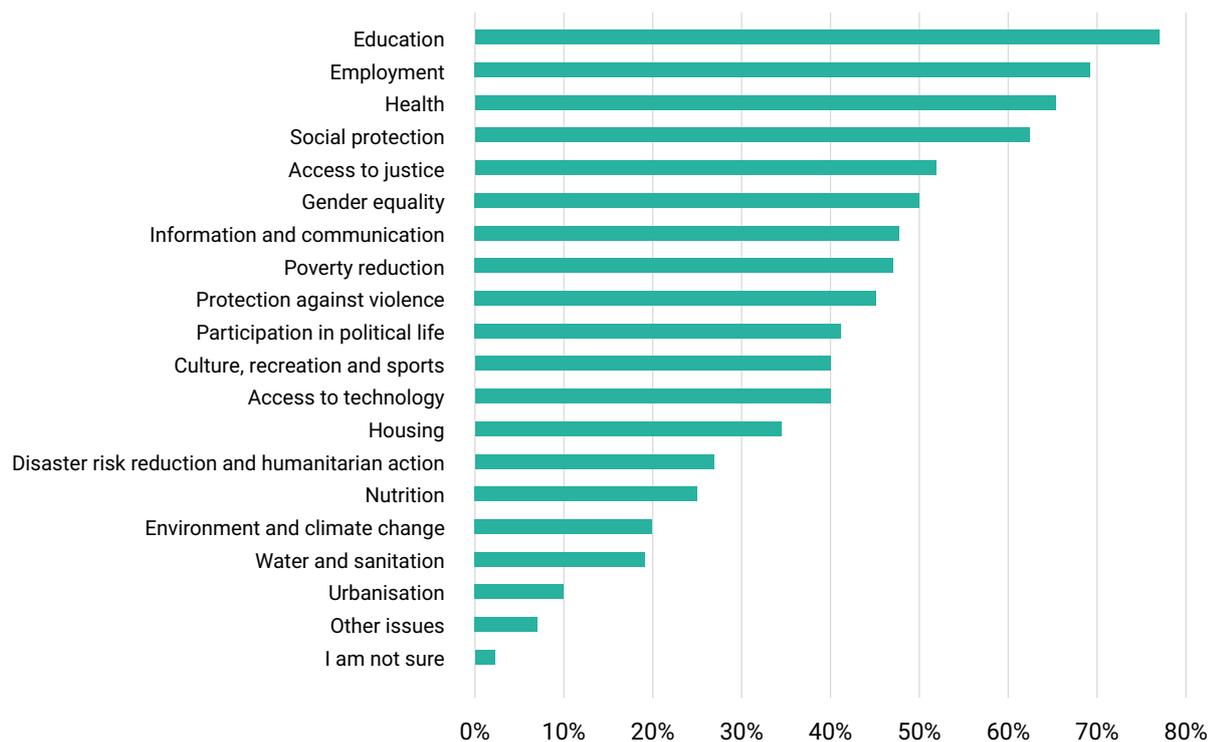


**Figure 27 – OPDs reporting they are consulted only on disability-specific issues in %; comparison between 1st and 2nd surveys**

OPDS REPORTING THEY ARE CONSULTED ONLY ON DISABILITY-SPECIFIC ISSUES, IN %	2018	2021
by government partners	81,79%	31,40%
by international partners	45,59%	44,70%

**Education, employment and health are clear priority issues of OPDs** – OPDs clearly indicated education, employment, health, social protection, and poverty reduction as their top priorities<sup>1</sup>. Issues ranked of least interest were urbanization, water and sanitation or environment and climate change. “Other” issues included ending negative stereotypes and stigmatization and discrimination, promoting self-determination/independence, and reforming legal systems (including prisoner rights, legal support, educating or reporting about human rights violations).

**Figure 28 – Priority issues for OPD respondents in %**



**Figure 29 – Priority issues for OPD respondents, in numbers (table)**

PRIORITY ISSUES FOR OPD RESPONDENTS IN #	RESPONSES
Education	654
Employment (jobs and work)	589
Health	546
Social protection	531
Access to justice	437
Gender equality	426
Information and communication	403
Poverty reduction	399
Protection against violence	384

Culture, recreation and sports	341
Access to technology	339
Participation in political life	345
Housing	287
Nutrition (healthy food)	222
Disaster risk reduction and humanitarian action	233
Environment and climate change	171
Water and sanitation (clean and safe water)	161
Urbanisation (growing cities)	87
Other	52
I am not sure	14

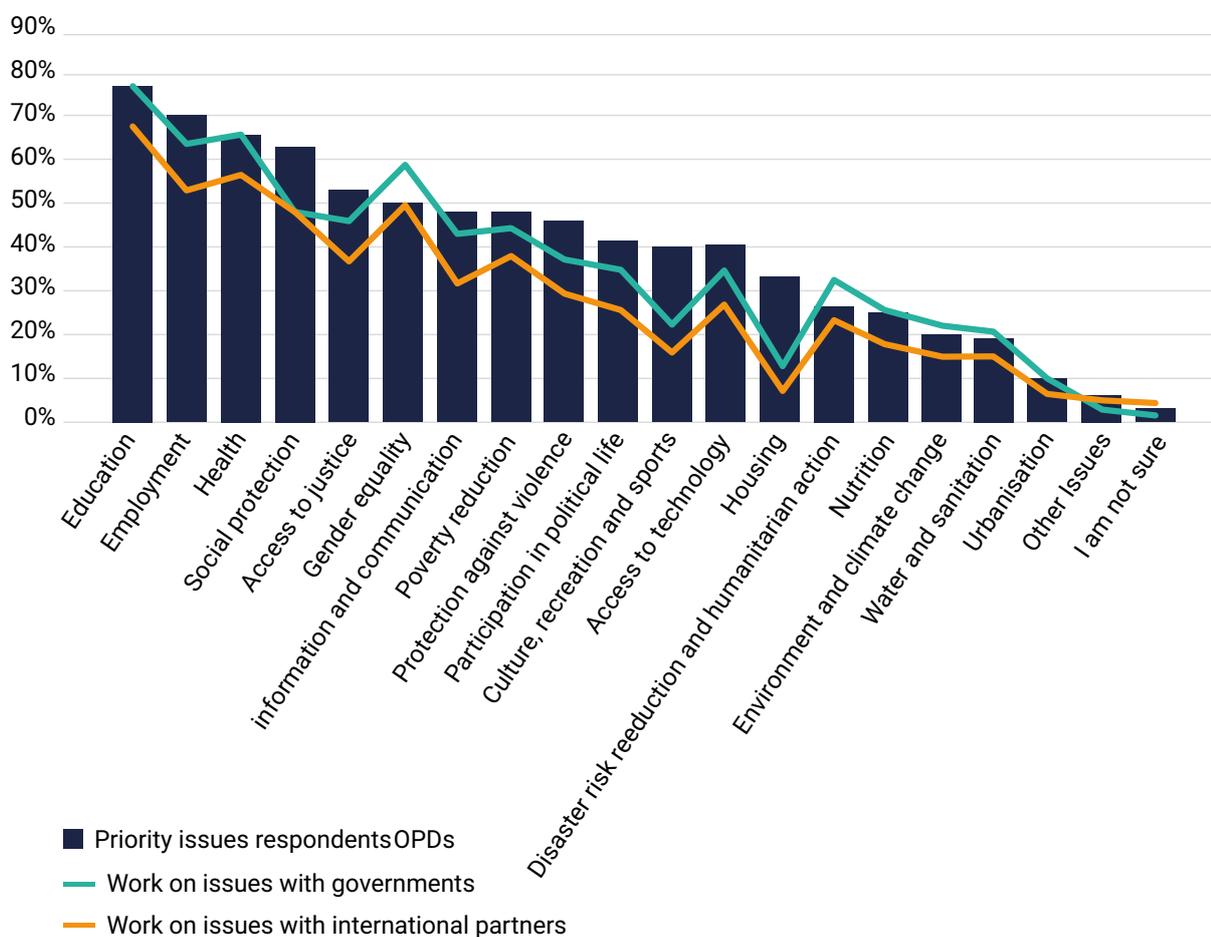
However, despite a positive trend, several respondents noted a perceived disconnect between the expressed intention to embrace an intersecting approach to leave no one behind and the reality of engagement and other's awareness of disability, for example:

*“It is incredibly frustrating to hear disability usually only/mainly brought up during disability-specific conferences and events. I have attended countless webinars, conferences, events, and speeches at and by UN entities and officials on large overarching topics (i.e., climate change, poverty reduction, etc.) and not once was disability or disabled people even mentioned. Mor[e] frustratingly, many times, the speaker(s) will talk about intersectionality but not once even mention disability or disabled people.”*  
*Respondent to the 2nd Global Survey*

### OPDs are usually involved on issues matching their priorities

Meaningful participation is a ‘means to an end’, i.e., a means to guarantee that public decision-makers develop policies, programmes, plans and projects in favour of the rights of persons with disabilities (Cote, 2020, p. 7). It is therefore important to compare issues on which OPDs are consulted and issues that are identified by OPDs as their own priorities (the 2nd Global Survey introduced new questions for this purpose). Figure 30 below shows a relative coherence between OPDs priorities and issues on which they are asked to contribute by governments and international partners.

**Figure 30 – Issues prioritized by OPDs vs issues on which they are consulted by governments and by international partners**



**Figure 31 – Issues prioritized by OPDs vs issues on which they are consulted by governments and by international partners, in %**

RELEVANCE OF ISSUES OF JOINT WORK WITH ALL ACTORS IN %	PRIORITY ISSUES FOR OPDs	ISSUES ON WHICH OPDs ARE INVOLVED WITH GOVERNMENTS	ISSUES ON WHICH OPDs ARE INVOLVED WITH INTERNATIONAL PARTNERS
Education	77,4	76,4	65,8
Employment	69,7	62,3	51,3
Health	64,6	63,4	54,2
Social protection	62,8	46,3	45,2
Access to justice	51,7	43,7	36,5
Gender equality	50,4	57,6	50,3

Information and communication	47,7	41,8	31,1
Poverty reduction	47,2	43,9	37,7
Protection against violence	45,4	37,7	29,1
Participation in political life	40,8	36,2	29,1
Culture, recreation and sports	40,4	26,8	21,2
Access to technology	40,1	35,5	27,8
Housing	34,0	16,5	12,6
Disaster risk reduction and humanitarian action	27,6	34,0	23,3
Nutrition	26,3	24,8	17,5
Environment and climate change	20,2	22,7	15,3
Water and sanitation	19,1	19,7	14,2
Urbanization	10,3	8,8	6,0
Other issues	6,2	2,6	4,9
I am not sure	1,7	2,6	4,1

In comparison with 2018, OPDs felt they were increasingly consulted on issues such as gender equality, education, health, and employment. Poverty reduction, environment and climate change, as well as nutrition have also gained more importance within joint work of OPDs with decision makers.

The highest disconnects concern housing; social protection; culture, recreation and sports; employment; protection against violence; access to justice; as well as information and communication. This suggests that **issues and services that are key enabling factors to persons with disabilities' participation and inclusion in their community are still insufficiently covered.**

These findings need to be nuanced by some comments highlighting a disconnect and dissatisfaction. As commented by a respondent from Uruguay *"efforts are not enough nor are they focused on the highest priority."*

Other sources of evidence collected by IDA and partners also show how the COVID-19 global pandemic significantly stretched OPDs' capacities as they many had to orientate their work towards responding to their members' emergency needs (compare e.g., IDA, 2021). As responses to the crisis often failed to include persons with disabilities, OPDs filled the gap and faced enormous opportunity costs, for example having to switch from ongoing advocacy priorities to instead focus on delivering first aid responses. Indeed, while OPDs are similarly affected by contextual factors that may foster or hinder civil society participation in general, in times of crisis, OPDs may be more affected than other civil society groups. As reported by FCDO and partners through a study on the impact of the COVID-19 pandemic on OPDs<sup>18</sup>: "instead of being invited to work with governments and humanitarian actors in disaster and response

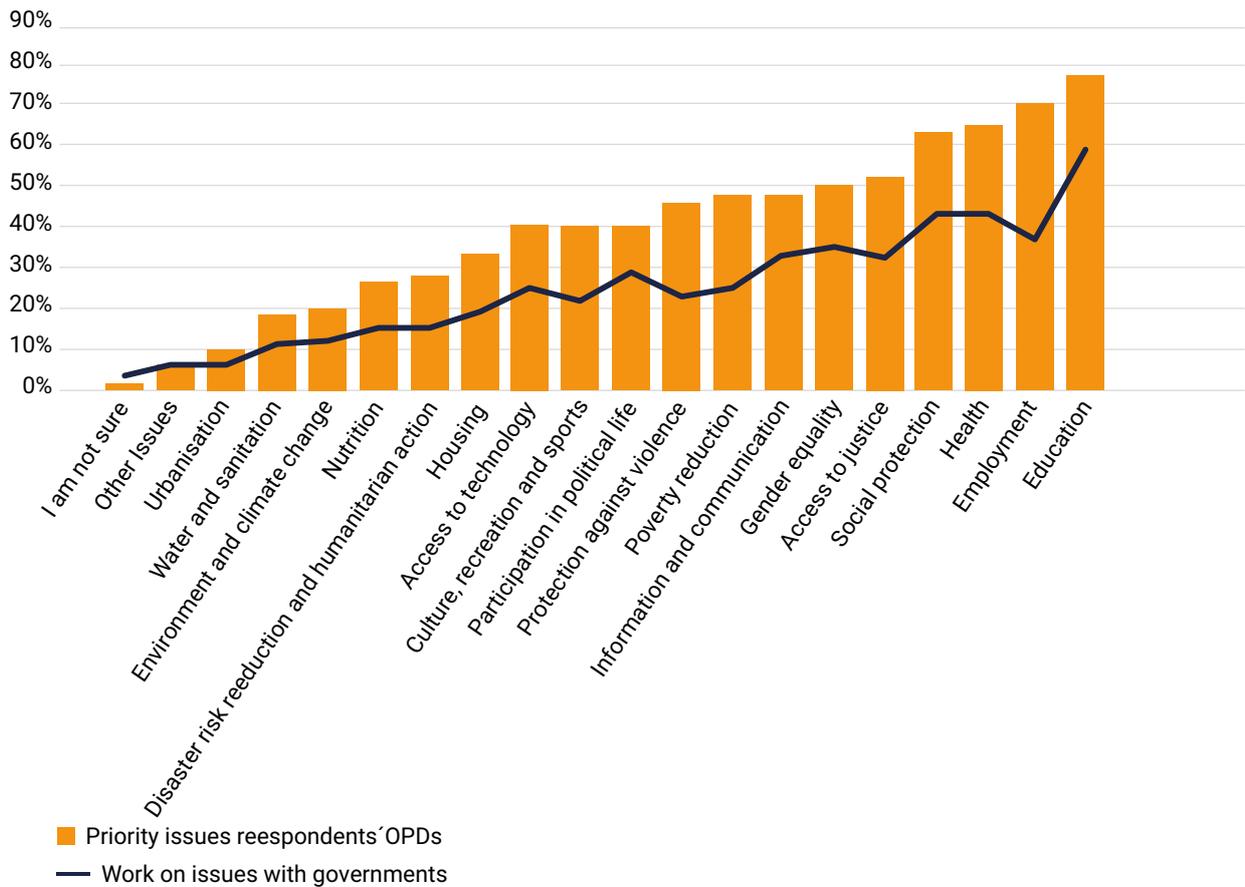
<sup>18</sup> Inclusive Futures (2021) Consequences of Exclusion: A Situation Report on Organizations of People with Disabilities and COVID-19 in Bangladesh, Nigeria, and Zimbabwe. <https://www.sddirect.org.uk/media/2268/english-situation-report-opds-covid-19-report-final.pdf>

planning, many OPDs found themselves trying to mitigate the consequences of policy decisions that had not adequately considered people with disabilities”.

### OPDs perceive they have impact on their priority issues

When comparing the level of perceived influence with the level of priority, OPDs tell us that overall, they do have more influence on topics that are of higher priority to them.

**Figure 32 – Perception of OPDs of their impact on their priority issues, in %**



**Figure 33 – Perception of OPDs of their impact on their priority issues, in %**

	<b>PRIORITY ISSUES FOR OPDs</b>	<b>ISSUES ON WHICH OPDs HAD AN IMPACT</b>
I am not sure	1,7	4,1
Other issues	6,2	4,9
Urbanisation	10,3	5,2
Water and sanitation	19,1	11,8
Environment and climate change	20,2	12,2
Nutrition	26,3	15,4
DRR and humanitarian action	27,6	15,7
Housing	34,0	18,9
Access to technology	40,1	25,8
Culture, recreation and sports	40,4	23,1
Participation in political life	40,8	28,2
Protection against violence	45,4	24,0
Poverty reduction	47,2	26,0
Information and communication	47,7	32,9
Gender equality	50,4	36,1
Access to justice	51,7	32,6
Social protection	62,8	45,6
Health	64,6	46,8
Employment	69,7	37,7
Education	77,4	59,0

## **Finding 3 - Participation remains limited in frequency and levels of shared decision-making, but is taking more formal pathways**

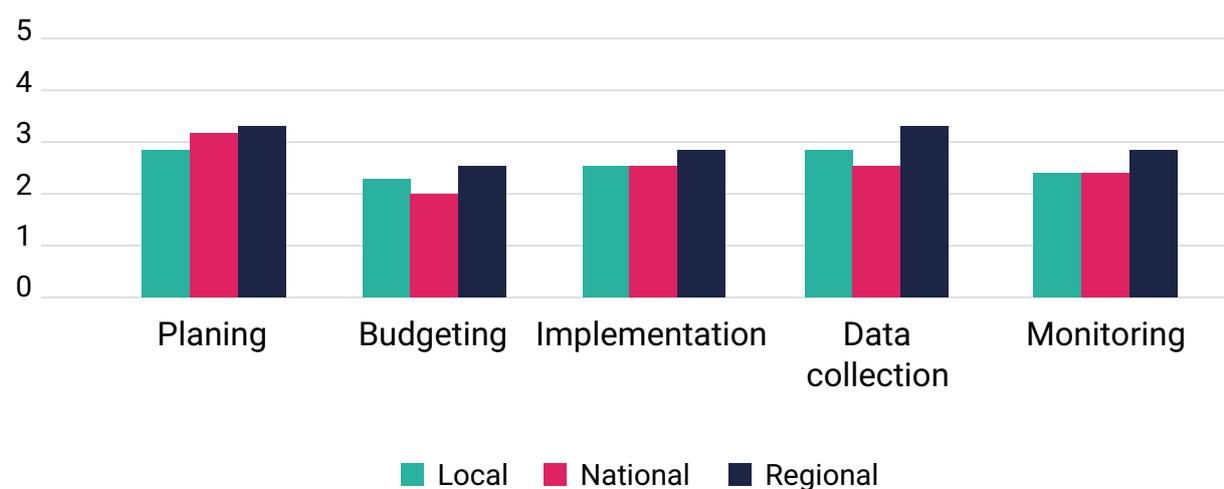
### **In summary:**

- Although slightly higher than in 2018, OPDs' levels of involvement in decision-making remain rather limited. A majority of OPDs report that they are only invited occasionally to participate in work with governments or international partners.
- Furthermore, they are less often involved in influential roles, especially when it comes to budget decisions (with 34,6% OPDs never invited to contribute on budgeting, and 26% never invited to contribute on monitoring and evaluation).
- OPDs are hardly ever involved as partners in co-decision making roles, either by governments or international partners.
- While participation takes place through more formal mechanisms, such as through having a seat at a national disability council, this may not result in actual influence on the outcomes of decision-making.
- This persisting trend of low levels of engagement does not apply to the United Nations, whose capacity to ensure preconditions for participation is perceived as stable or slowly increasing. This encouraging finding echoes the progress self-reported by the UN system against the objectives set by the UN Disability Inclusion Strategy (UNDIS), three years after its launch.

## Frequency of OPD engagement remains very low

On average, OPDs report that they are only sometimes invited to participate in joint work, whether with local, national governments, or with regional integration bodies. Budgeting remains an area for which an average of 34,2% OPD respondents report that they are never invited (41,4% for national level government). Monitoring and evaluating public policies and programs also show low levels of reported engagement, with 26% of OPDs reporting in average that they are never invited. Regional decision makers seem to show a slightly more systematic engagement.

**Figure 34 – Average frequency of engagement of OPDs in work with governments on all levels (bar chart) – on a rating scale ranging from 1 (never) to 5 (always)**

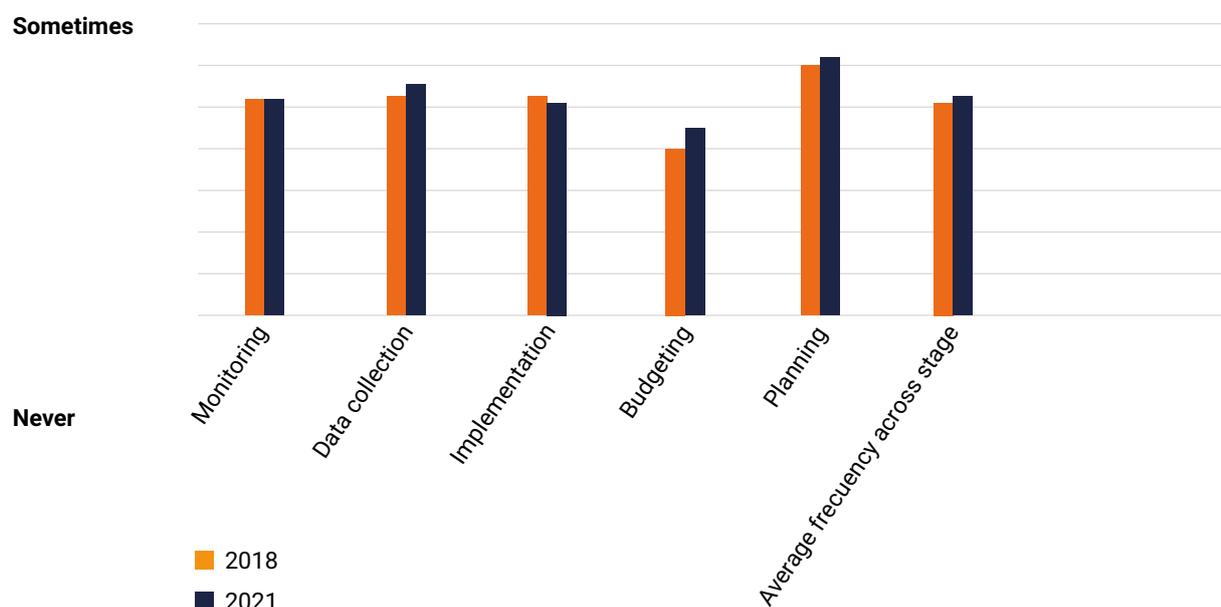


**Figure 35 – Average frequency of engagement of OPDs in work with governments on all levels, from 1-5 (table) – on a rating scale ranging from 1 (never) to 5 (always)**

AVERAGE FREQUENCY OF INVOLVEMENT IN WORK OF ALL ACTORS	LOCAL	NATIONAL	REGIONAL
Planning	2,9	3,1	3,2
Budgeting	2,3	2,0	2,5
Implementation	2,5	2,5	2,8
Data collection	2,8	2,5	3,2
Monitoring	2,4	2,4	2,9

As compared with 2018 in Figure 36 and 37 below, the frequency of involvement with different stakeholders has increased minimally or remained the same. As commented by a respondent from Nigeria, frequency remains very low overall: “often we were not invited to [...] actively participate in most of the plannings”.

**Figure 36 – Average frequency of OPD engagement with local, national and regional government by stage, evolution over time**

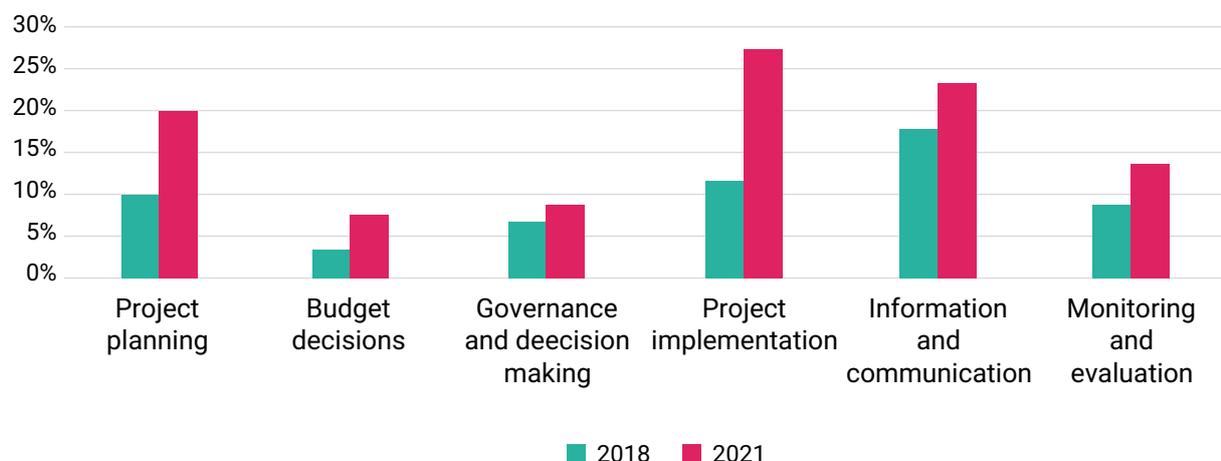


**Figure 37 – Average frequency of OPD engagement with local, national and regional government by stage, evolution over time**

<b>AVERAGE FREQUENCY OF OPD ENGAGEMENT WITH LOCAL, NATIONAL AND REGIONAL GOVERNMENT BY STAGE, OVER TIME</b>	<b>2021</b>	<b>2018</b>
Monitoring	2,6	2,6
Data collection	2,8	2,7
Implementation	2,6	2,7
Budgeting	2,3	2
Planning	3,1	3

### Positive evolutions with the UN

Although participation with the UN remains limited in scope, a positive evolution is clearly perceived by OPDs who have experience of engagement, as reflected in figure 38 below. This can likely be attributed to the incentive created by the UN Disability Inclusion Strategy (UNDIS, launched in 2019) and its accountability framework, which requires yearly reporting against a set of indicators for systemic disability mainstreaming, including an indicator on consulting with persons with disabilities (indicator 5).

**Figure 38 – Evolution of OPD engagement with the UN across stages, in %****Figure 39 – Evolution of OPD engagement with the UN across stages, in % (table)**

<b>EVOLUTION OF OPD ENGAGEMENT WITH THE UN ACROSS STAGES, IN %</b>	<b>2018</b>	<b>2021</b>
Project planning	10	19,9
Budget decisions	3	7,2
Governance and decision making	7	8,5
Project implementation	12	26,9
Information and communication	18	23,5
Monitoring and evaluation	9	14,5

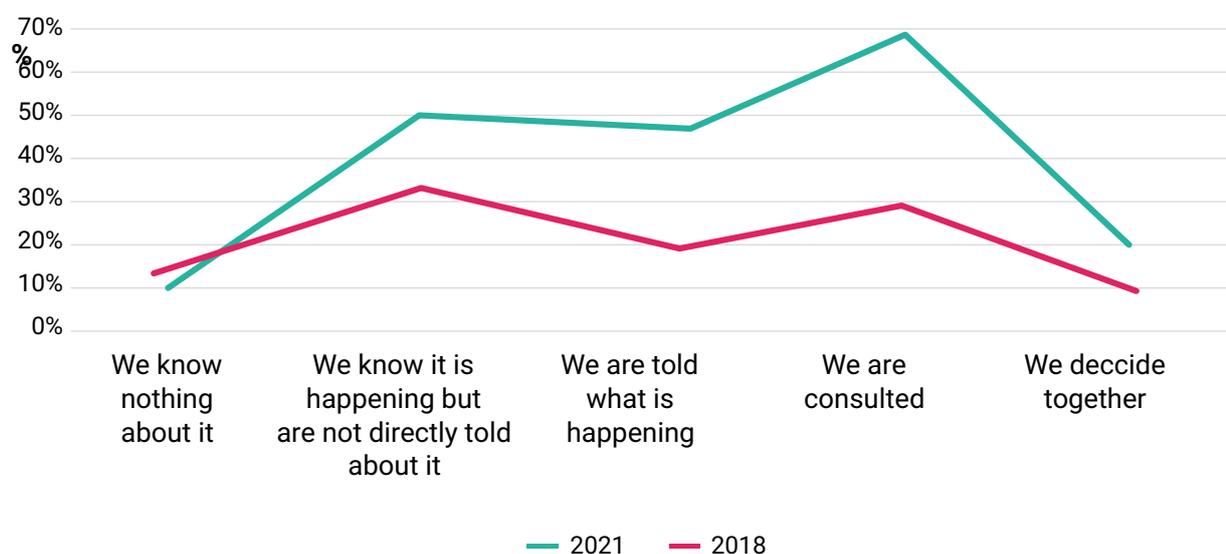
### Levels of shared decision-making remain very low

Meaningful participation is partly determined by the level of shared decision-making in the relationship between OPDs and their counterparts.

Similarly, to the frequency of engagement, the level of shared decision-making is low, although with a slight improvement from 2018. OPDs report that, while they are somehow aware of what is happening, they are too often not informed and very rarely consulted or co-deciding. The following figures illustrate evolutions across stages of the program or policy cycle:

## Planning

**Figure 40 – Evolution of OPD shared decision-making in planning with governments, in**

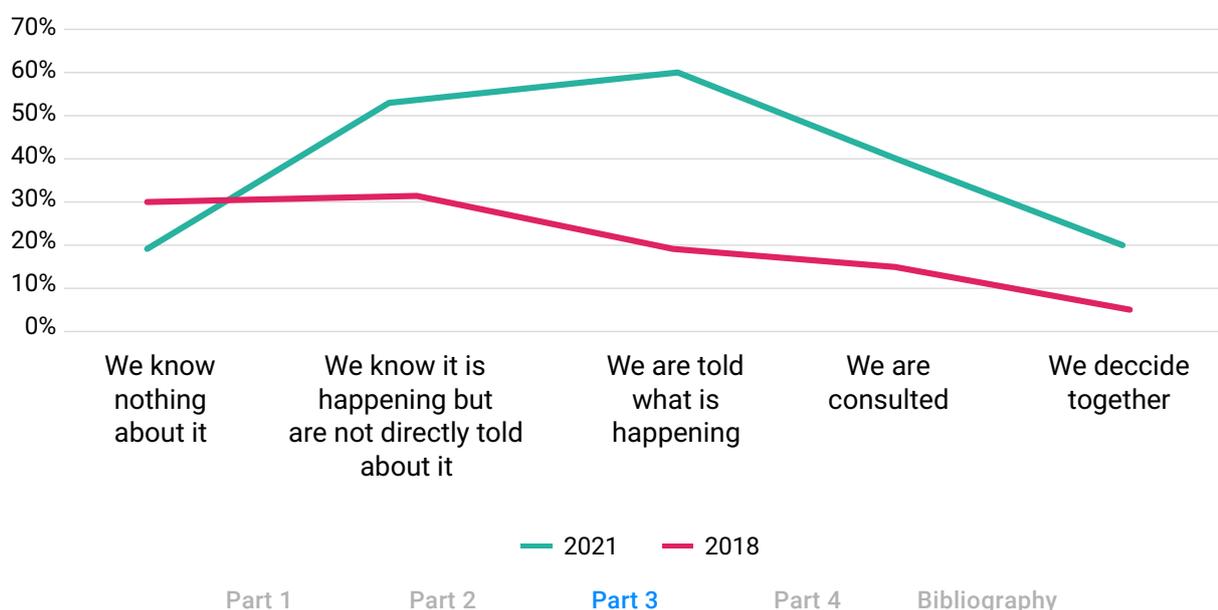


**Figure 41 – Evolution of OPD shared decision-making in planning with governments, in %**

LEVEL OF SHARED DECISION-MAKING IN PLANNING STAGE	2021	2018
We know nothing about it	9	11
We know it is happening but are not directly told about it.	48	33
We are told what is happening	47	18
We are consulted	68	30
We decide together	21	9

## Budgeting

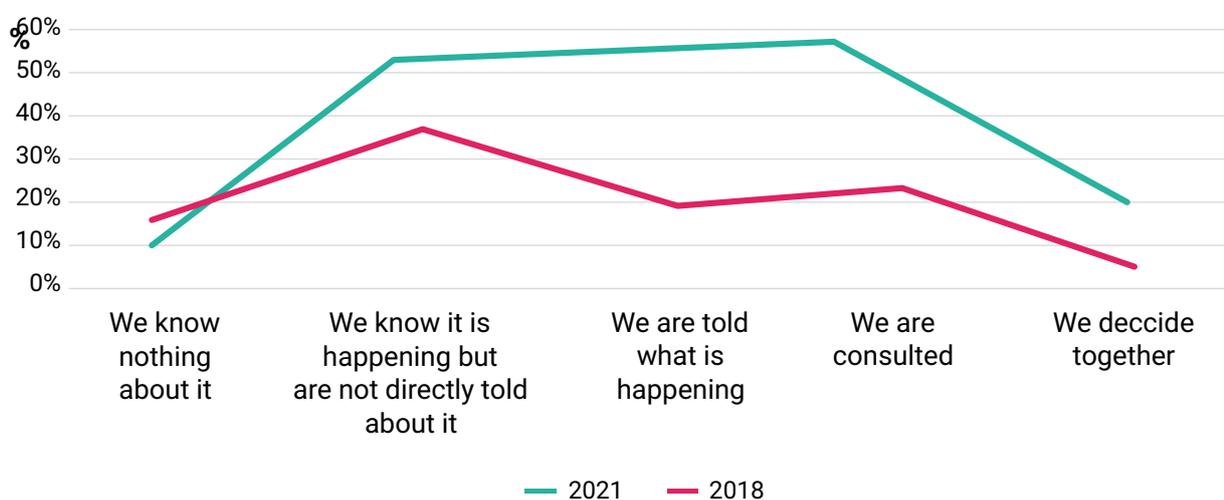
**Figure 42 – Evolution of OPD shared decision-making in budgeting with governments, in %**



**Figure 43 – Evolution of OPD shared decision-making in budgeting with governments, in %**

LEVEL OF SHARED DECISION-MAKING IN BUDGETING STAGE	2021	2018
We know nothing about it.	20	30
We know it is happening but are not directly told about it.	53	31
We are told what is happening	60	20
We are consulted	42	15
We decide together	18	4

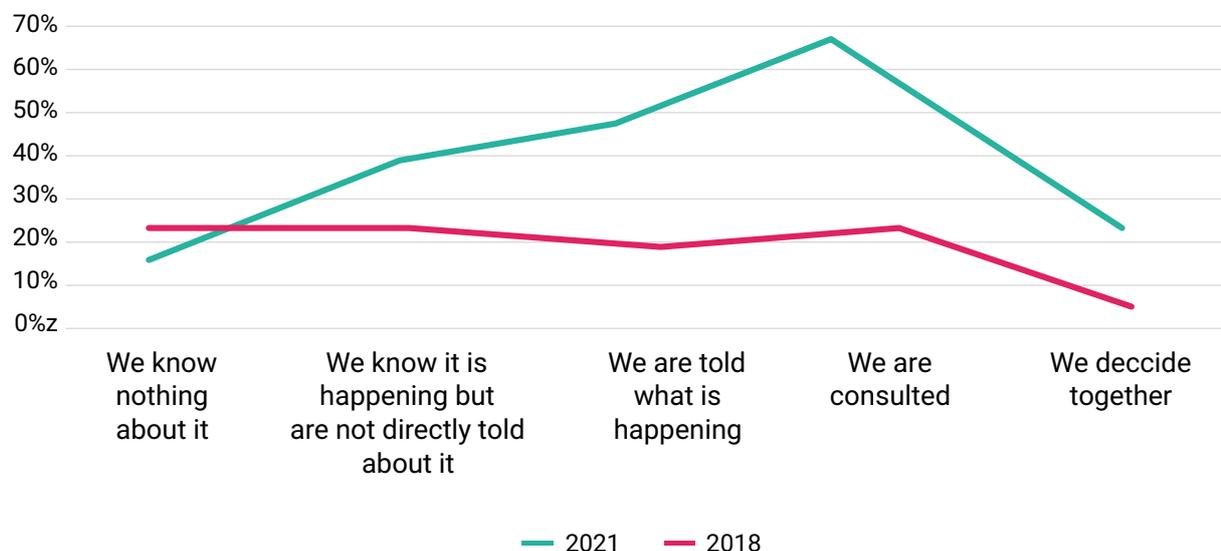
## Implementation

**Figure 44 – Evolution of OPD shared decision-making in implementation with governments, in****Figure 45 – Evolution of OPD shared decision-making in implementation with governments, in %**

LEVEL OF SHARED DECISION-MAKING IN IMPLEMENTATION STAGE	2021	2018
We know nothing about it.	10	14
We know it is happening but are not directly told about it.	54	38
We are told what is happening	55	19
We are consulted	57	23
We decide together	19	6

## Data collection

**Figure 46: Evolution of OPD shared decision-making in data collection with governments, in %**

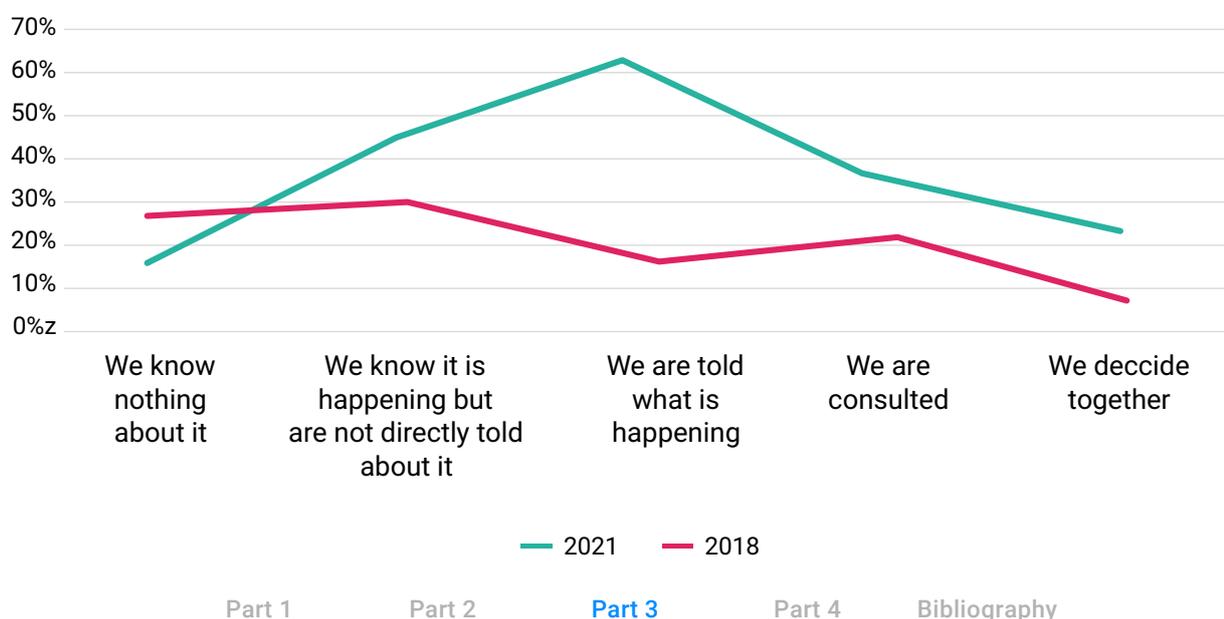


**Figure 47 – Evolution of OPD shared decision-making in data collection with governments, in %**

LEVEL OF SHARED DECISION-MAKING IN DATA COLLECTION STAGE	2021	2018
We know nothing about it.	15	23
We know it is happening but are not directly told about it.	37	24
We are told what is happening	50	18
We are consulted	67	27
We decide together	24	8

## Monitoring

**Figure 48 – Evolution of OPD shared decision-making in monitoring with governments, in %**



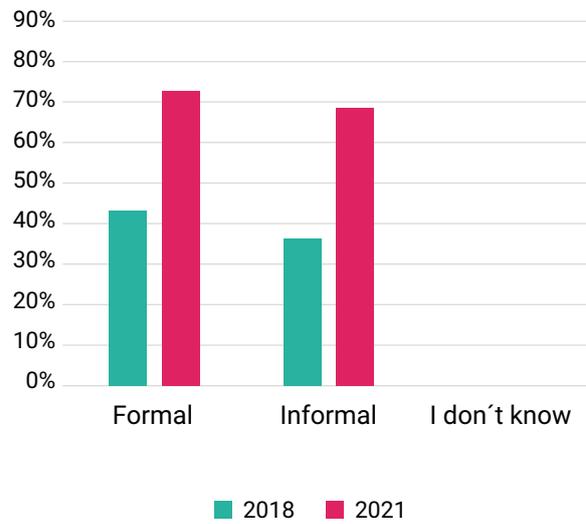
**Figure 49 – Evolution of OPD shared decision-making in monitoring with governments, in %**

LEVEL OF SHARED DECISION-MAKING IN DATA COLLECTION STAGE	2021	2018
We know nothing about it.	16	26
We know it is happening but are not directly told about it.	44	29
We are told what is happening	62	17
We are consulted	39	21
We decide together	24	6

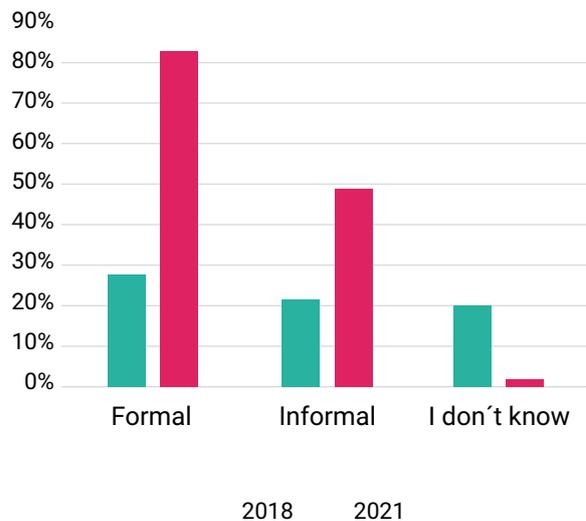
**Ways in which OPDs are consulted by governments are more formally established**

One proxy indicator to analyse evolution of OPD participation are the mechanisms through which this participation takes place. As decision makers set more formal mechanisms, such as a seat for OPDs at a national disability council, consulting with OPDs becomes part of a regular process and may be given more consistent consideration, at least on paper. The degree of formality of consultation mechanism does not necessarily result in more effective participation. In some cases, this may even be a way for decision-makers to tick the box without ensuring preconditions for meaningful contributions from OPD representatives, and/or without effectively giving more weight to their views.

**Figure 50 a – Ways in which OPDs engage with governments**



**Figure 50 b – Ways in which OPDs engage with international partners**



**Figure 51 – Ways in which OPDs engage with governments and with international partners, in %**

WAYS OF OPD WORK WITH ALL ACTORS IN %	GOVERNMENTS 2018	GOVERNMENTS 2021	INTERNATIONAL PARTNERS 2018	INTERNATIONAL PARTNERS 2021
formal	43,1	74,8	27,2	82,6
informal	36,1	67,7	22,0	49,6
I don't know	8,0	0,0	20,7	1,3

## Finding 4- Many groups of persons with disabilities are still left behind in decision-making

### In summary:

- Groups who are more frequently involved in decision making are persons with physical impairments, deaf persons or persons who are blind or partially sighted. Persons with deafblindness, persons with intellectual disabilities, persons with psychosocial disabilities and hard of hearing persons are involved to a much lesser extent.
- Groups who are the least involved are persons affected by leprosy, persons with a chronic disease, persons of short stature, persons with epilepsy, albinism or vitiligo.
- As such, there is no evidence for greater involvement in decision making for many groups of persons with disabilities between the first and second survey.

Persons with disabilities are not a homogenous group. Not only are experiences of persons with disabilities very different, but the diversity of situations in which they experience difficulties is also influenced by multiple identity factors; such as gender, age, geographic location, indigenous identity, sexual orientation, and poverty. In line with the principle of leaving no one behind, analysing participation of OPDs requires attention to this

diversity and to the discrepancies in participation of the diverse constituencies represented by OPDs.

OPD respondents asked about groups they perceive to be involved by governments and international partners do not perceive any major difference – with the exception of a higher representation of persons with physical impairment, indigenous persons with disabilities and less representation of hard of hearing persons in work with government as compared to international decision-makers.

Without major change from the 1st (2018) to the 2nd Global Survey (2021), respondents report that:

- Groups who are the **most involved** are persons with physical impairments, persons who are blind and partially sighted and deaf persons
- Groups who are **involved but to a much lesser extent** are persons with intellectual disabilities, persons with psychosocial disabilities and persons deafblindness
- Groups who are **the least involved** are persons with affected by leprosy, persons with a chronic disease, persons of short stature, persons with epilepsy, albinism or vitiligo (people with pale skin patches)

It is important to bear in mind that involvement of different groups may be influenced by the prevalence of these groups in different contexts, as well as terminology and categories used for classification.

Comments by respondents identify clear hierarchies among OPDs in advocacy resources, social capital and involvement in decision-making:

*"[Those who] have good lobby are everywhere, the others are nowhere" Respondent from Germany*

*"People with visible disabilities are more often involved, as well as those who are 'heard'." Respondent from Russia*

*"People with intellectual disabilities [are] viewed with suspicion when they disclose their disability." Respondent from Zimbabwe working on international level*

*"Indigenous persons with disabilities and persons with high support needs including persons with psychosocial disabilities are not involved." Respondent from Bangladesh*

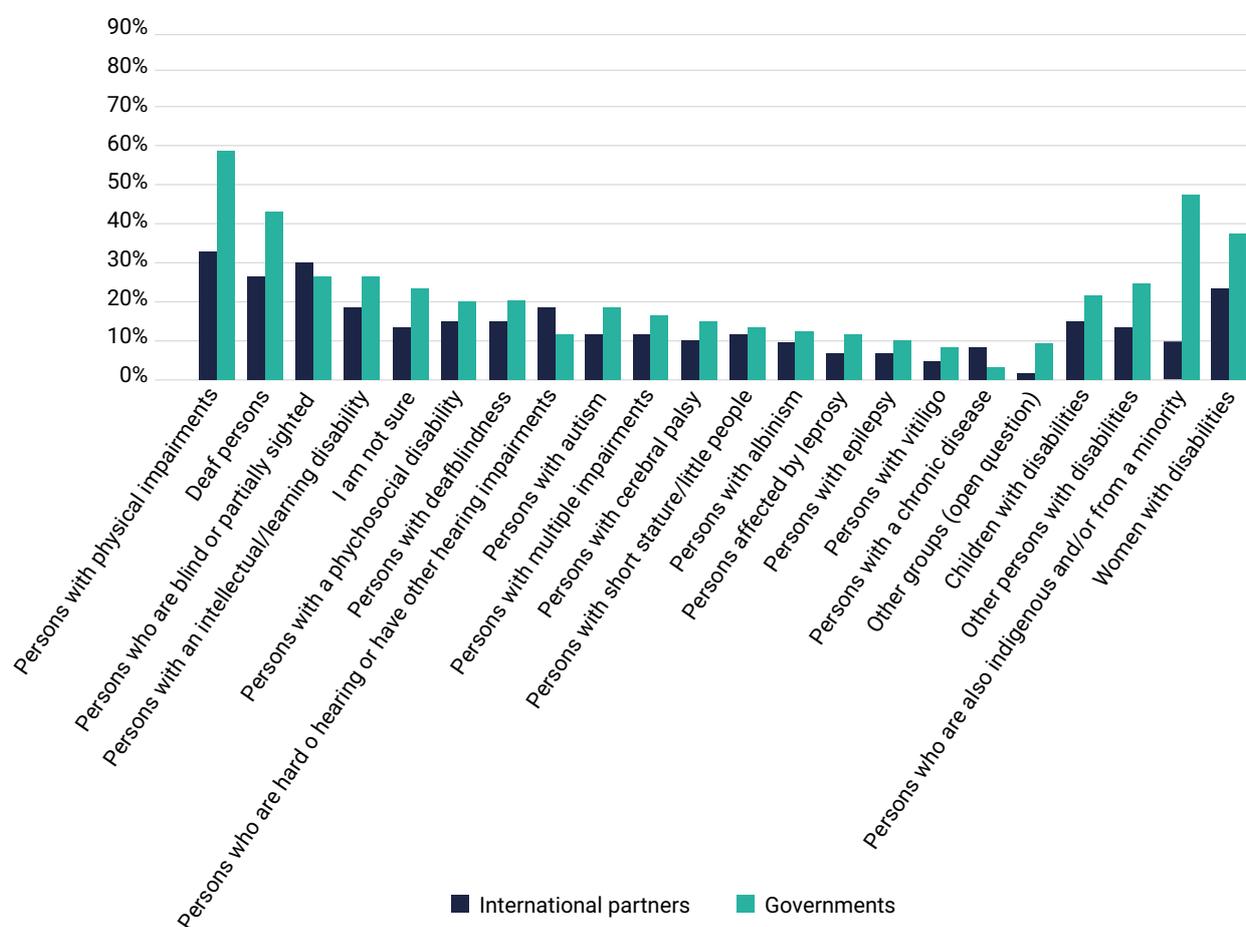
*"The invitations are usually for those close by." Respondent from Nigeria*

*"Persons with a lower capacity are completely excluded, because only stronger OPDs have access to international partners. This is mostly the case with persons with intellectual and psychosocial disabilities as well as persons with hearing impairment, because they do not have the adequate knowledge of English and organisational skills, due to barriers in formal and non-formal education." Respondent from Montenegro*

Respondents also identify unequal representation of different groups as a limitation to good participation and leaving no one behind:

*"The limited number of groups participating [...] means that the objectives of the involvement cannot be fully realized as different group have different needs" Respondent from Nigeria.*

**Figure 52 – Groups of persons with disabilities involved by governments and international partners, in % (bar chart)**



**Figure 53 – Groups of persons with disabilities reported to be involved by governments and international partners, in %**

GROUPS INVOLVED IN WORK WITH ALL ACTORS IN %	INTERNATIONAL PARTNERS	GOVERNMENTS
Persons with physical impairments	32,7	58,7
Deaf persons	26,8	42,5
Persons who are blind or partially sighted	30,4	28,7
Persons with an intellectual/ learning disability	17,3	25,3
I am not sure	12,6	22,2
Persons with a psychosocial disability	13,9	20,2
Persons with deafblindness	13,8	19,9
Persons who are hard of hearing or have other hearing impairments	18,9	11,5
Persons with autism	11,6	18,9

Persons with multiple impairments	11,8	17,4
Persons with cerebral palsy	10,3	17,1
Persons with short stature/ little people	10,7	15,9
Persons with albinism	9,8	15,2
Persons affected by leprosy	6,0	14,0
Persons with epilepsy	6,3	10,2
Persons with vitiligo	4,2	6,3
Persons with a chronic disease	6,3	3,6
Other groups (open question)	0,7	9,1
Children with disabilities	14,2	20,3
Older persons with disabilities	13,3	22,3
Persons who are also indigenous and/or from a minority	10,4	47,1
Women with disabilities	23,8	36,0

## Finding 5 - Preconditions for participation, such as accessibility adjustments and reasonable accommodation, is perceived to have deteriorated overall

### In summary:

- In comparison to three years ago, when preconditions for participation were already not good, OPDs perceive a greater setback in ensuring physical accessibility and informational-communicational accessibility in 2021.
- Positive attitudes and knowledge of decision makers on what is required for meaningful OPD participation are perceived as significantly lower than in the first Global Survey.
- While 14% of respondents for the first survey reported that provision of funding for

reasonable accommodation was not ensured at all, the percentage of respondents reporting this actually increased to 41% in 2021.

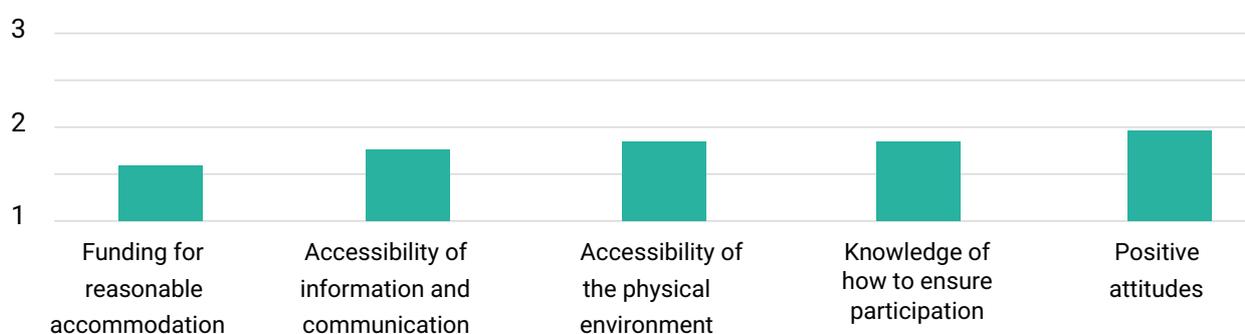
- As the scope of issues on which OPDs are consulted has broadened overall, it is likely that stakeholders engaging for the first time with OPDs are less familiar with the requirements of persons with disabilities to participate on an equal basis with others. The intention to include, but without experience of how to include, may create discriminatory consultation practices.

*“Lack of availability and funding for personal assistance, lack of information in easy-to-read version, lack of accessibility of websites and electronic documents, tokenism on behalf of government in terms of giving little weight to comments of persons with disabilities in the public consultations, lack of understanding and expertise among key personnel in the government on CRPD.”*  
Respondent from Serbia

Results from the second IDA Global Survey show that the CRPD obligations to ensure non-discrimination by ensuring accessibility and provision of reasonable accommodation is far from being achieved. Respondents very clearly flag a significant gap between their requirements to participate and how these requirements are met by governments and international partners.

For example, **41,5% of the OPD respondents report a total lack of funding for reasonable accommodation**. Among preconditions, positive attitudes and knowledge on what is required for meaningful OPD participation, appear to have decreased most significantly. A possible interpretation is that while OPDs get more involved with decisionmakers, those who newly get involved with OPDs still lack the experience how to provide for an enabling and meaningful decision-making environment. In addition to this, and as OPDs get more knowledgeable about their human rights, they expect more from duty-bearers and so are more aware of the gap between commitments taken and their realization.

**Figure 54 – Provisions for accessibility and reasonable accommodation by governments, in average (bar chart) - on a rating scale ranging from 1 (not at all) to 3 (fully)**

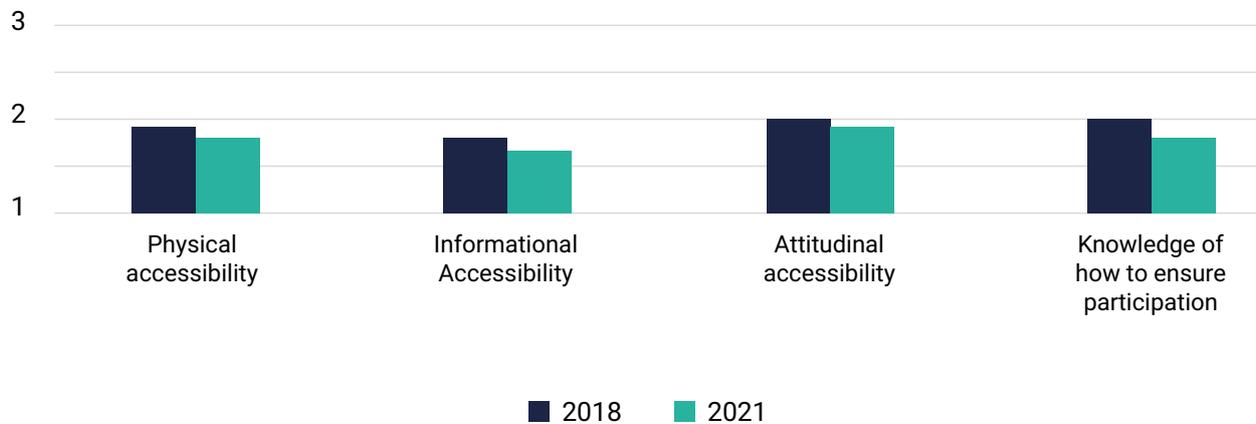


**Figure 55: Provisions for accessibility and reasonable accommodation by governments, in %**

PROVISIONS FOR ACCESSIBILITY AND REASONABLE ACCOMMODATION BY GOVERNMENTS IN %	Accessibility of the physical environment	Accessibility of information and communication	Positive attitudes international partners 2018	Knowledge of how to ensure participation	Funding for reasonable accommodation
Not at all	26,2	30,7	19,9	24	41,5
In some ways	62,6	58,8	65,6	60,2	45,8
Fully	5,4	5,5	10,3	9,8	6,1
I am not sure	5,8	5,0	4,2	6,0	6,7

While the involvement with decision makers has increased overall in comparison to 2018, levels of accessibility and provisions for reasonable accommodation within joint work with governments are perceived to have decreased.

**Figure 56: Evolution of preconditions for participation ensured by governments, on average (bar chart) – on a rating scale ranging from 1: not at all to 3: fully**



**Figure 57: Evolution of preconditions for participation ensured by governments, from 1: not at all to 3: fully**

PRECONDITIONS FOR OPD PARTICIPATION ENSURED BY GOVERNMENTS	2018	2021
Physical accessibility	1,9	1,8
Informational accessibility	1,8	1,7
Attitudinal accessibility	2	1,9
Knowledge of how to ensure participation	2	1,8

Comments by OPDs reflect a wide diversity of challenges related to securing preconditions:

PRECONDITIONS FOR OPD PARTICIPATION ENSURED BY GOVERNMENTS	ILLUSTRATIVE QUOTES
Physical accessibility	<i>"Inaccessible places, therefore people with physical disabilities cannot access." (respondent from Panama)</i>
Informational accessibility	<i>"Only a few documents are digitally accessible." (Respondent from Venezuela)</i> <i>"Sometimes there are no [sign language] interpreters, or Braille, or plain language." (respondent from Panama)</i>

<p><b>Positive attitudes towards persons with disabilities</b></p>	<p><i>"It is not so much the accessibility of the offices but the political will."</i> (respondent from Colombia)</p> <p><i>"Negative attitude of some decision makers."</i> (respondent from Rwanda)</p> <p><i>"Prejudices and stereotypes, adherence to the medical model, a deficit approach and the priority of charity, rather than providing conditions for functioning."</i> (respondent from Russia)</p>
<p><b>Knowledge of how to ensure participation</b></p>	<p><i>"Transparency lack of dialogue [and] lack of understanding of problematic issues of people with disabilities."</i> (respondent from Kazakhstan)</p> <p><i>"Deadlines are usually far too short. Often only three to four days. Disabled people and the associations that represent them are often not invited and do not receive any allowance for expenses."</i> (respondent from Venezuela)</p> <p><i>"Many DPOs do not have the financial means to travel at all times and participate in work and other meetings."</i> (respondent from Chad)</p>
<p><b>Funding for reasonable accommodation</b></p>	<p><i>"Disabled people and the associations that represent them [...] do not receive any allowance for their additional expenses."</i> (respondent from Venezuela)</p> <p><i>"[Lack of] capacity building, funding for OPD/DPOs to participate on an equal basis with others, etc."</i> (respondent from Ireland)</p> <p><i>"More UN agencies are aware of the reasonable accommodations to be provided for persons with disabilities but still do not always have the budget for providing these measures."</i> (respondent from Finland)</p>

## Finding 6 - OPDs continue to lack capacities, resources and opportunity to meaningfully engage

### In summary:

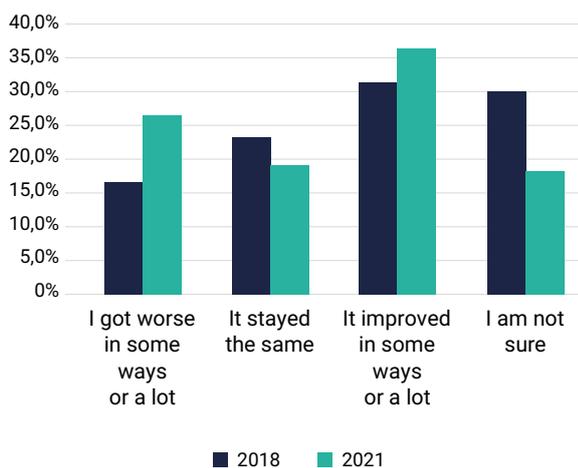
- Respondents explained that their organisations often lack experience and knowledge about decision-making processes. OPDs often have too few activists to be influential with decision-makers in all areas where they need to intervene.
- OPDs lack time, training and experience as well as financial and human resources to meaningfully engage.
- This is sometimes compounded by legal barriers to establish and register an organization.
- A negative circle that is difficult to break hence perpetuates their exclusion by depriving OPDs of opportunities to strengthen their capacity to participate.
- Power dynamics at play, both within and beyond the disability rights movement, keep some groups away, as they are perceived to have lower capacity to influence decision makers.

- There is often a lack of recognition for OPDs' expertise, and a concern that non-representative disability organizations and sometimes parents are still too often in leading roles, or speak on behalf of OPDs instead of fostering more collaborative processes.

### OPDs lack access to financial resources, which they receive primarily from INGOs as intermediaries

When asked about evolutions in funding, 36% of OPDs report that it improved in some ways or a lot, while for 26,8% it deteriorated and for 19% it stayed the same. This provides a mixed picture and further analysis would be required to understand if there are particular patterns associated with contexts and levels at which OPDs operate. As compared with three years ago, OPDs are more aware of funding evolutions and a higher proportion of them report decreased access to financial resources.

**Figure 58: Change in OPD funding, in % (bar chart)**



**Figure 59: Evolution of OPD funding, in %**

CHANGE IN OPD FUNDING, IN %	2018	2021
It got a lot worse or it got worse in some ways	16,0	26,8
It stayed the same	23,0	19,0
It improved in some ways or a lot	32,0	36,0
I am not sure	30,0	18,2

Funding received by OPDs mainly comes from International Non-Governmental Organisation (INGOs) (38,7%), followed by governmental funding agencies (24,7%) and foundations (22,7%). 31,4% of the respondents' from OPDs also work with other funding agencies and donors such as humanitarian actors, development banks, or private companies. While more OPDs are aware of their funding sources than in 2018, there is no shift in the types of donors that fund OPDs as a priority, with INGOs being the main source overall.

OPDs are appreciative of the funding received, as commented by a respondent from Guatemala: *"our international partners are private non-profit organizations and we have enlisted their support to fund our work. They have understood the cultural difference and respect it. That allows us to do our job but we can always improve."* However, some respondents express a frustration that OPDs do not access funding from donor agencies directly, but rather through INGOs as intermediaries. For example, a respondent from Bangladesh explained: *"Donors do not work with us directly. We do not have any direct connection with them. We are engaged by NGOs or CBOs who are funded by donors. Therefore, we do not have any opportunity to work with them or to take part in the consultation with them."*

Others flag the barriers of strict funding conditionalities that prevent OPDs from accessing funding: *"They are too rigid with their money."*

*Some strings attached are too had for persons with disabilities at [t]he grass roots. Sometimes persons with disabilities are not involved directly” (respondent from Uganda).*

Overall, there is a shared feeling that financial resources are insufficient to enable OPDs to operate and fulfil their mandate.

### **OPDs’ capacities are over-stretched and power dynamics limit OPDs’ opportunities to engage**

OPDs describe that their organisations often lack experience and knowledge about decision-making processes. OPDs often have too few trained experts to cover policy and advocacy priorities. Opportunity costs already flagged in the first IDA Global Survey are getting greater for OPDs, as requests increase and diversify. As OPDs succeed in getting disability on the agenda, the scope of issues on which they need to engage also gets broader. As commented by respondents: “Our organisation is far overstretched capacity wise [...]. We have contributed to significant achievements, that in turn creates more work” (respondent from Norway); “While overall satisfied, more engagement and capacity development in country is needed.” (respondent from Fiji).

Insufficient funding is not the only constraint: “Self-organized disabled people at this time need more technical than financial support ... we need them to help us self-manage so that the impact of our voices is greater, so that our efforts are recognized, and our experiences are validated.” (Respondent from Peru). As they newly engage and have not had access to prior opportunities, OPDs need to develop their capacities. Newer issues such as humanitarian action require the understanding of different ways of operating. This investment in building OPDs as stronger development and humanitarian counterparts is often overlooked: “It [cannot be] taken for granted that persons with disabilities have knowledge and understanding [...], thus there is a need for capacity building and

increasing skills [...] for OPDs.” (Respondent from Lithuania).

Lack of reasonable accommodations and understanding of the preconditions necessary for meaningful engagement (as explained above) results in inadequate timing for OPD contributions. “Deadlines are usually far too short. Often only three to four days.” (respondent from Venezuela).

Overall, OPD respondents express concern about the persisting exclusion of certain groups of persons with disabilities which have had lower opportunities to acquire capacity to influence decision makers.

OPD respondents also express their concern about persisting leadership by parents and non-OPD groups, who they felt are too often acting on behalf of persons with disabilities. The stronger agency and capacity to engage of such groups was not always seen as being in the interests of OPDs. Patronizing behaviours prevail: “When any regional government or intervention plan is made, we [...] are never called upon and medical professionals and parents who claim to represent our interests take highly discriminatory and potentially harmful measures for our differences, based on a medical model and without really taking into account human rights.” (respondent from Peru).

## **Finding 7 - The COVID-19 pandemic disproportionately impacted persons with disabilities, and also impacted on the work of OPDs**

### **In summary:**

- The majority of OPDs reported that they experienced challenges due to the pandemic,

which has also impacted their participation in decision-making processes, sometimes halted funding and created new challenges to participate in the digital world.

- A few respondents cited positive changes such as new forms of virtual connections and activism, or new engagement in disability-inclusive emergency response.
- However, overall, it was found that the pandemic increased the poverty of persons with disabilities or threatened their health, reducing capacities for activism.
- Opportunity costs identified through the first survey were exacerbated in times of crisis. As expressed by a respondent, “there is more work, but less funding.”

The COVID-19 pandemic that hit the world unexpectedly in 2020 had alarming consequences for all populations. However, as the crisis amplified pre-existing inequalities, persons with disabilities were disproportionately affected. IDA and partners analysed this impact in the early stages of the pandemic through the Disability Rights Monitor COVID-19, which disclosed the fatal consequences of societies’ failure to include persons with disabilities in emergency responses. In 2021, IDA ran another survey on the Experiences of Persons with Disabilities Adapting to the COVID-19 Global Pandemic, addressing more specifically the situation of underrepresented groups of persons with disabilities, which showed the long-term discriminations faced by persons with disabilities in addressing the socio-economic consequences of the pandemic (IDA, 2021). Furthermore, in partnership with FCDO and Inclusive Futures, IDA contributed to collect qualitative evidence on the

impact of COVID-19 on OPDs<sup>19</sup> in three countries. As pointed out by OHCHR in its report on Good practices and challenges faced by States in using the guidelines on the effective implementation of the right to participate in public affairs, persons with disabilities continue to encounter significant barriers to the exercise of their right to participate in public affairs, a situation worsened by the pandemic which also affected related human rights such as the right to access information, or to freedom of expression and peaceful assembly.

The second IDA Global Survey provides additional views from OPDs on their experience of dealing with this global health crisis. Consequences of the COVID-19 are reported by OPDs on three main levels, relating to the overall approach to disability, capacity and resources to engage, and the shift to the digital world.

### **A setback with the human rights approach to disability**

Consistent with other findings, the majority of respondents report challenges for their constituencies in all areas of life, and how this increased challenges for OPDs’ work: “COVID-19 has exacerbated already existing vulnerabilities by stopping activities, funding, donations. This situation has increased the poverty of people with disabilities” (respondent from Mali). “COVID19 was a magnifying glass on the problems of people with disabilities who were there before the crisis.” (respondent from Austria).

Discriminations experienced by persons with disabilities from most marginalized groups were amplified during the COVID-19 pandemic: “Mentally disabled people and people with dementia have been locked up in nursing homes and have not been allowed to leave or let their friends and relatives in since the beginning of the

<sup>19</sup> 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>

pandemic. These people have been forced to stay segregated and isolated if their families could not keep them with them at home (for a variety of reasons). They were penalized much more than all other citizens, so there were much more calls for help from families and all segregated people who could speak.” (respondent from Italy).

The pandemic revealed how in times of crisis, commitments to inclusion are fragile and societies easily revert to entrenched negative behaviours:

*“The negative [change] is the decline in acquired rights, many times there have been loss of rights, and many other times a welfare perspective has prevailed and not under the paradigm of the rights of people with disabilities as subjects of rights”* (respondent from Uruguay).

*“The support provided to people with disabilities has collapsed and the government’s priorities have changed so that people with disabilities have become a more marginalized circle, unfortunately.”* (respondent from Oman).

*“There is no positive change, since the violation of rights has increased with the excuse of the pandemic.”* (respondent from Honduras)

*“There is a new excuse to maintain segregation or isolation and it is necessary to activate strong actions to return.”* (respondent from Colombia)

### **Capacities and resources to engage further stretched**

Participation of OPDs in shaping public policies and programs was largely halted during the COVID-19 pandemic. The work of OPDs slowed down in all areas, including due to personal challenges faced by their individual members and lack of access to support services: “unfortunately for deafblindness the support of an interpreter guide is vital and if it was already difficult, the pandemic has plunged us into something much

more difficulty” (respondent from Venezuela).

The state of emergency pushed OPDs to embrace new roles to compensate for the gaps of a disability-inclusive response, stretching capacities to the maximum. As expressed by a respondent from Russia, “the workload on the team has roughly doubled”. A positive outcome has been a greater recognition of OPDs’ contribution in emergency contexts. “The lockdown impact on our work has been the most severe negative change. Due to restrictions related to social distancing, persons with deafblindness in general was isolated from day one, as there is a base need for personal contact with interpreter-guides. Even though the situation improved somewhat, it still impacted our ability as an OPD to reach out to our members, to support them, or keep them informed of the current situation. It also impacted our ability to uphold a sound governance structure. On the positive side, the same restrictions provided us with an opportunity to develop new terms, like “digital interpreter-guide services” that allowed for interpreter-guides to assist also in an increasingly online world. This term was acknowledged by the government, and we are now working on a full and lasting implementation of this term, and the interpretation of the term.” (respondent from Norway).

However, OPDs report an overall decrease in and diversion of available funding for development, and a higher workload with less funding support. “The main negative change of COVID-19 in the work of my organization has been the sharp reduction in funding as well as the increased vulnerability of its beneficiaries!” (respondent from Rwanda). “There is more work, but less funding.” (respondent from Kyrgyzstan).

### **Challenges and opportunities of the shift to the digital world**

The pandemic also transformed ways of working, with a significant shift to the digital world. In low- and middle-income countries where the majority of persons with disabilities live, the digital gap

they experience is disconcerting. OPDs express grievances when it comes to inaccessibility of online communication platforms and lack of inclusive online work practices.

- *“Those affected could not be reached digitally. Therefore, the greatest challenge is still digitalization.”* (respondent from Germany)
- *“We have to move to virtuality and many do not have a cell phone or computer and others live without internet.”* (respondent from Colombia)
- *“Most often, all of this is done virtually and many DPOs do not have the material and financial capacity to bear these costs.”* (respondent from Chad)

However, when accessibility barriers could be overcome, the shift to the virtual world has also created new opportunities for OPDs to engage, where participation was previously restricted by the size of a room, inaccessibility of venues, or costs of travel. Some also report that they used virtual challenges to raise awareness and succeeded in securing greater online accessibility and attention to inclusive and accessible communication.

- *“The positive has been that, due to the virtual meetings, more women with disabilities around the country have joined our organization.”* (respondent from Ecuador)
- *“The participation of people with limited mobility in working groups has been greatly facilitated, with participation rates 2 to 3 times higher.”* (respondent from Switzerland)
- *“More events to which we are invited – now there are no restrictions on the number of participants.”* (respondent from Russia)
- *“The favourable change is that through virtuality we have been able to participate in*

*very important international events, which otherwise would have depended on specific financing that is not always easy to obtain.”* (respondent from Uruguay)

- *“Our OPD was born out of the frustrations a group of online friends had due to COVID restrictions hurting PWDs the most. We went from online friends, to a collective, and now a registered organisation in just one year. We are connected nationwide by increased digital connectivity due to the needs for non-disabled to work from home.”* (respondent from Malaysia)

The experience of OPDs during the Covid-19 pandemic therefore reinforces the need for a much stronger social justice orientation to be taken to digital accessibility and training, so that the Sustainable Development Goals can be achieved in a more equitable manner, leaving no one behind (O’Sullivan et al, 2021). The Global Report on Assistive Technology (WHO/ UNICEF, 2022) has also highlighted how digital and assistive technologies play a vital role in the claiming of rights and in the protection of those rights under emergency situations. The findings of our Global Survey supports these views.

The second IDA Global Survey on OPD participation, and the comparison it allows for the first time with data collected in 2018, shows some positive changes, but also a slow and unsteady path towards meaningful OPD participation. As OPDs’ influence is growing but their satisfaction is not, it is important to go beyond an apparent paradox: more participation does not necessarily mean better participation.

The COVID-19 pandemic and multiple crises affecting democracy and human rights also create less conducive contexts for civil society engagement. Moreover, with an increased understanding of their human rights, OPDs have increased expectations from their governments. These expectations are not being met and OPDs are becoming increasingly impatient with the lack of progress in collaboration and consultation –

# 4 Recommendations

and de facto with progress in the implementation of their human rights. This most likely explains the decrease in satisfaction in OPDs working with their governments.

In contrast, OPDs are positive about being increasingly approached by international partners, even if this collaboration is not always meaningful or balanced in terms of power. This may be explained by the global momentum for disability inclusion, fostered by the Global Disability Summits and the UN Disability Inclusion Strategy, which opens new collaborations, where OPDs were previously overlooked as development and humanitarian action partners.

A clear overall message from OPDs for governments and international partners is that there continues to be a significant under-investment in ensuring the preconditions for OPD participation to be meaningful. As the rationale for engaging with OPDs is stronger, the implications of this shift in practice are only starting to be understood. From ensuring accessibility to addressing unequal power dynamics within projects, from strategies to truly leave no one behind, to equipping OPDs to grow and thrive as representative organizations – more needs to be done to enact promises. Commitments need to be matched with investments in OPDs as key partners to turn these rights into actions.

## Recalling that meaningful participation should...

- **respect, value and consider the unique role and perspective of OPDs as representative organizations;**
- **enable their regular and effective engagement, by ensuring equal opportunities for all to contribute;**

- **seek the highest levels of shared decision-making on all issues that concerns all persons with disabilities,**

...this report highlights [6 key recommendations](#), which are equally relevant to governments and international partners:

### 1. **Ensure higher levels of OPD participation in decision making and give more weight to their contribution, from the design stages onward**

When invited to contribute, OPDs are too often invited to participate in programmes that have already been designed without their inputs and are being asked to mostly to support outreach and awareness activities. Instead, OPDs should be invited to take part in policy and program design from the outset. Rights-based, inclusive programming requires that they are not only informed or consulted, but also considered for partnership roles, with clear opportunities to frame and influence decisions. OPDs should be given clear roles matching their priorities. There should be more investment in their capacity, from advocacy to technical training. Accountability adds quality to participatory processes: opinions shared by OPDs should be given due weight, feedback should be provided on how their contributions were used, and feedback should be sought on how participation could be improved.

### 2. **Remove legal barriers to participation and accelerate investments in support services that enable participation**

Governments should remove legal barriers to the participation of persons with disabilities and repeal discriminatory laws and policies

that prevent their equal recognition before the law and equal opportunities to participate. Accountability should be ensured through measures to enforce anti-discrimination in practice. Structural barriers such as lack of accessibility and lack of support services to enable participation and inclusion should be addressed. This may be done through accessibility law and policy and increased investment in developing services that provide the 'missing link' for persons with disabilities' participation, including human assistance, access to assistive technology, accessible transportation, or disability-inclusive social protection that effectively compensate for the extra costs incurred by persons with disability.

### **3. Ensure systematic accessibility and provision of reasonable accommodation in all consultation facilities and processes**

Governments and international partners need to systematically ensure accessibility of all consultation facilities and processes for all persons with disabilities, including through reasonable accommodation. This includes choosing accessible venues or teleconference technologies, ensuring accessible information and communication about opportunities to participate, ensuring accessible information and communication during the consultation through captioning, national Sign Languages and understandable formats, and ensuring adequate time for preparation and engagement. Co-designing processes for consultation with OPDs can lead to more effective engagement and outreach.

### **4. Support OPDs to access funding and opportunities to develop their organization**

Participation of OPDs should be properly resourced, not only through covering the costs of accessibility and reasonable accommodations in consultations, but also by investing in OPDs to equalize their opportunity to engage and contribute as partners. Investing in OPDs should consider proportionate funding conditionalities (for example, adapting due diligence requirements to the size of organization), accessible application procedures (for example in different several languages and formats) and capacity building in fundraising. OPDs should have access to adequate core funding and resources to support their existence, operations, organisational development, capacity to coordinate with their members and advocacy priorities and perform their role(s) with independence, autonomy and adequate capacity.

### **5. Invest in and learn from OPDs' technical capacities**

OPDs demand better support, to improve their organizational, technical capacities and leadership. This is particularly important for organizations of underrepresented groups and OPDs operating in rural areas. Participation in decision-making supports OPDs to learn and acquire the skills and agency to contribute more efficiently. Therefore, government and international partners should invest in a virtuous circle, whereby creating opportunities to learn and engage will result in higher-level contributions from OPDs. Capacity building in the area of international

cooperation (for example, understanding of humanitarian response processes, project management, emerging issues such as climate change, etc.) also supports OPDs' relevance and efficiency as development partners. Furthermore, decision-makers should also learn from OPDs, not only as voicing the demand on behalf of persons with disabilities, but also as source of technical expertise and know-how on rights-based disability-inclusive responses.

address power dynamics and seek to promote collaboration with cohesive cross-disability voice for greater impact.

#### **6. Proactively support participation of the diversity of constituencies, especially underrepresented groups**

Leaving no one behind requires attention to all persons with disabilities, and proactive efforts to reach out to those furthest behind and overcome barriers that may prevent underrepresented groups of persons with disabilities from engaging. Persons with deafblindness, persons with intellectual disabilities, persons with psychosocial disabilities, persons with invisible disabilities such as being hard of hearing, and persons with disabilities facing intersecting forms of discrimination, such as women, children, youth, older and indigenous persons with disabilities require particular attention. Decision-makers should invest in OPDs as a movement, promoting unity (for example, respecting the leadership of a national cross-disability federation as the main national interlocutor) and diversity (for example, providing extra support to ensure active engagement of underrepresented groups). Indicators should be used to track progress and ensure accountability on meaningful inclusion of all. Participation and consultation modalities should be designed in ways that acknowledge and

# Bibliography

Australian Aid/ DFAT (2018): Creating a new 'Business as usual': Reflections and lessons from the Australian aid program on engaging disabled people's organisations in development programming and humanitarian action. Online available at: <https://did4all.com.au/Uploads/CreatingANewBusinessAsUsualDPOEngagementInDevelopment.pdf> (accessed on 18.02.22).

Cote, A. et al (2020): Towards meaningful participation of Organisations of Persons with Disabilities in the implementation of the CRPD and SDGs. A pilot study by Bridging the Gap. Available online at: [The-unsteady-path.-A-pilot-study-by-BtG.pdf](https://www.bridgingthegap-project.eu/files/2020/06/The-unsteady-path.-A-pilot-study-by-BtG.pdf) (bridgingthegap-project.eu) Madrid: Bridging the gap project (accessed on 18.02.22).

General Assembly (2007). Convention on the Rights of Persons with Disabilities, A/RES/61/106. available online at: [A/RES/61/106: Convention on the rights of persons with disabilities](https://www.un.org/en/content/61/106/convention-on-the-rights-of-persons-with-disabilities) (un.org) (accessed on 18.02.22)

IDA (2020): Increasingly Consulted but not yet Participating. IDA Global Survey on Participation of Organisations of Persons with Disabilities in Development Programmes and Policies. Available online at: <https://www.internationaldisabilityalliance.org/blog/increasingly-consulted-not-yet-participating-ida-global-survey-report-participation> (accessed on 18.02.22)

IDA (2021): IDA Survey on the Experiences of Persons with Disabilities Adapting to the COVID-19 Global Pandemic. Executive Summary and Recommendations. Available online at: <https://www.internationaldisabilityalliance.org/content/ida-survey-experiences-persons-disabilities-adapting-covid-19-global-pandemic> (accessed on 01.03.22)

Inclusive Futures (2021): Consequences of Exclusion. A Situation Report on Organisations of People with Disabilities and COVID-19 in Bangladesh, Nigeria, and Zimbabwe. Available online at: <https://www.sddirect.org.uk/media/2268/english-situation-report-opds-covid-19-report-final.pdf> (accessed on 18.02.22).

O'Sullivan, K., Clark, S., Marshall, K., and MacLachlan, M. (2021) A Just Digital framework to ensure equitable achievement of the Sustainable Development Goals. *Nat Commun* 12, 6345 (2021). Available online at: <https://doi.org/10.1038/s41467-021-26217-8>

UN (1948): Universal Declaration of Human Rights. New York: UN. Available online at: <https://www.un.org/en/about-us/universal-declaration-of-human-rights> (accessed on 25.02.22).

UN (1996-2021): International Covenant on Civil and Political Rights. Geneva: OHCHR. Available online at: <https://www.ohchr.org/EN/ProfessionalInterest/Pages/CCPR.aspx> (accessed on 25.02.22).

UN (2019): United Nations Disability Inclusion Strategy. N.I.: UN. Available online at: <https://www.un.org/en/content/disabilitystrategy/> (accessed on 18.02.22).

UN Committee on the Rights of Persons with Disabilities (2018): General comment No. 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.

UN, Office of the High Commissioner for Human Rights (2018): Guidelines for States on the effective implementation of the right to participate in public affairs. Available online at: [https://www.ohchr.org/sites/default/files/Documents/Issues/PublicAffairs/GuidelinesRightParticipatePublicAffairs\\_web.pdf](https://www.ohchr.org/sites/default/files/Documents/Issues/PublicAffairs/GuidelinesRightParticipatePublicAffairs_web.pdf) (accessed on 18.02.22).

WHO/UNICEF (2022) Global report on assistive technology. Geneva: World Health Organization and the United Nations Children's Fund (UNICEF), Licence: CC BY-NC-SA 3.0 IGO

