

Executive Summary | March 2022

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)

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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.

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**¹. 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.**

¹ <https://www.sddirect.org.uk/media/2268/english-situation-report-opds-covid-19-report-final.pdf>

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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, with satisfaction increasing on engagement with international partners but decreasing on engagement 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, 81,7% 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 pathways

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 the 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."

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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 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 questions 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 organisation

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.