

Increasingly Consulted, but not yet Participating



Executive Summary

IDA Global Survey on Participation of Organisations of Persons with Disabilities in Development Programmes and Policies, 2020.

Acknowledgements

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Background: a global momentum towards disability inclusion

Participation of citizens is a fundamental principle of democratic societies. It supports good governance and social accountability¹, by allowing people to influence and exert control over decisions that affect their lives. Yet due to attitudinal, legal, physical, economic, social and communication barriers to their participation in society, persons with disabilities are very often left out of decision-making processes and decisions are made on their behalf. **The exclusion of persons with disabilities from decision-making processes perpetuates and exacerbates their exclusion from all areas of society.** When their perspectives are systematically ignored, this leads to public policies and programmes that are not responsive, not effective and continue to hinder their rights.

The disability rights movement demanded and took a very active part in negotiating and drafting the Convention on the Rights of Persons with disabilities (CRPD). As the result of the influence and decisive role played by persons with disabilities in developing the text of this treaty, **the CRPD enshrines the effective and meaningful participation of persons with disabilities at its core.** In particular, Article 4.3 of the CRPD legally anchors the obligation for States to closely consult and actively involve persons with disabilities, including children with disabilities, through their representative organisations. This obligation applies at all levels (local, national, regional, international), in all areas that directly or indirectly impact the rights of persons with disabilities and across all decision-making mechanisms. This also applies to international cooperation, which should be inclusive of and accessible to persons with disabilities (as recalled by CRPD Article 32). The CRPD also stresses the **importance of organisations of persons with disabilities (OPDs²) as representative organisations and intermediary bodies between policy makers and persons with disabilities**, who bring a unique perspective to speak on behalf of persons with disabilities.

Since the adoption of the CRPD, major changes have been secured in how persons with disabilities are viewed and considered in societies and in generating new commitments to include persons with disabilities, such as in the 2030 Agenda for Sustainable Development, or through the adoption of the UN Disability Inclusion Strategy. While this global momentum is very positive, there is a significant risk that well-intended pledges 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. **Participation of persons with disabilities, through their representative organisations, is therefore essential to guide reforms and transformations** required by commitments to include.

As pointed by the CRPD Committee, significant gaps remain in realising the spirit of Article 4.3 and the absence of meaningful involvement of persons with disabilities and their representative organisations in the development and implementation of policies and programmes³. In other words, increased commitments to include 'disability' do not necessarily result in inclusion of organisations representing

persons with disabilities in decisions that concern them.

¹ A/HRC/31/62, para. 13.

² The questionnaire used Disabled People's Organisations (DPOs) and respondents also use this terminology. The terminology Organisation of Persons with Disabilities (OPDs), preferred by IDA and used by the CRPD Committee, is used across the report except when directly quoting respondents or sections of the original questionnaire.

³ CRPD/C/GC/7 para 8.

The IDA Global Survey: an accountability tool to monitor OPD participation

Against this background, the International Disability Alliance (IDA) felt the acute need to collect broader evidence and analyse the reality of OPD's engagement in decision-making. **The IDA Global Survey was therefore developed 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. It is meant to become **a regular tool to measure progress, learn from what works, know where to improve, to strategize advocacy and support ongoing efforts.** IDA's intention is that the Global Survey can be a regular global OPD-driven accountability exercise to take the pulse of participatory practices by government, UN agencies and funding agencies, as perceived by OPDs.

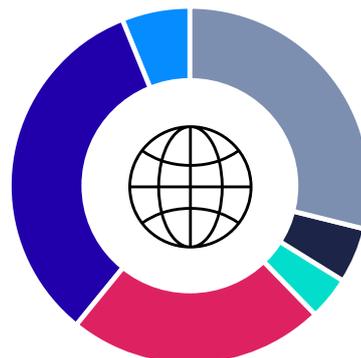
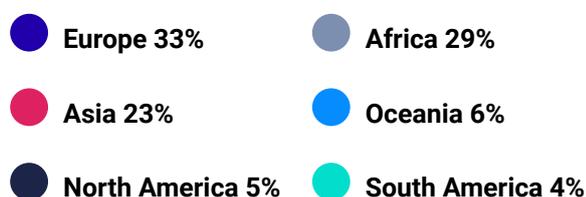
Participation is a complex alchemy and combination between the capacity of OPDs to articulate demands, invest in or claim space and the willingness and capacity of decision-makers to consult and effectively give consideration to their views. To understand how effective OPD participation is, and how to make it more meaningful, **the IDA Global Survey aims to provide the unique perspective and experience of OPDs themselves.** It aims to analyse different dimensions of participation, including:

- 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: which are the issues on which OPDs are consulted?
- How: are preconditions for participation ensured?
- When: at which stages of the policy or programme cycle are OPDs consulted?
- How often: is participation regular or occasional?
- How formalised: 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 Survey was tested with a group of persons with disabilities who also commented on its accessibility. The questionnaire was developed in English plain language and was disseminated online, in Arabic, Chinese, English, French, Russian, Spanish and International Sign. Responses were received from **573 OPD respondents from 165 countries across all regions**, of which a large majority (54,5%) works at the national level.

Figure a – Regions in which OPD respondents work.

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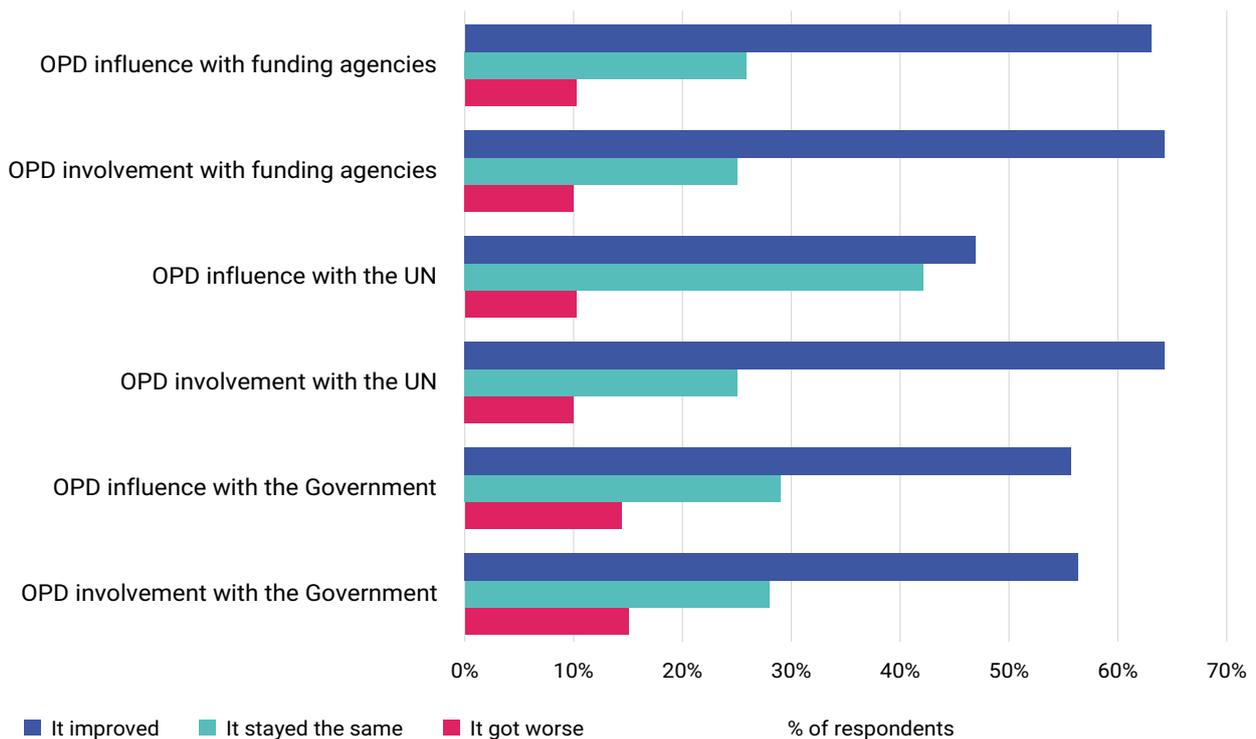


Key findings: increasingly consulted, but not yet participating

Survey results provide for the first time at this scale an impression of the experience of OPDs and a unique perspective from the disability rights movement on their perception of the CRPD obligation to closely consult with and actively involve persons with disabilities in decision-making processes, including through international cooperation. It provides evidence that further supports trends observed elsewhere and regularly discussed by IDA and its members, including:

Participation of persons with disabilities, through their representative organisations, is increasing overall. As civil society space is shrinking globally, disability issues are nonetheless still progressing on the agenda; this is possibly due to the global momentum created over the last few years, and/or owing to a comparatively lower starting point, and/or to disability being a less sensitive or political divisive than other social and human rights issues.

Figure b – Evolution of OPD involvement and influence with government, UN and funding agencies, as compared to one year ago.



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

There are organizations which are more or less listened to and funded, but as far as I know the organizations of people with mental disabilities are not as influential as the others.

— Survey respondent from Lithuania.

The adjustments are limited and minimal... In the Netherlands, disability equals «wheelchair» and that is where the focus is regarding disability and accessibility.

– Survey respondent from the Netherlands

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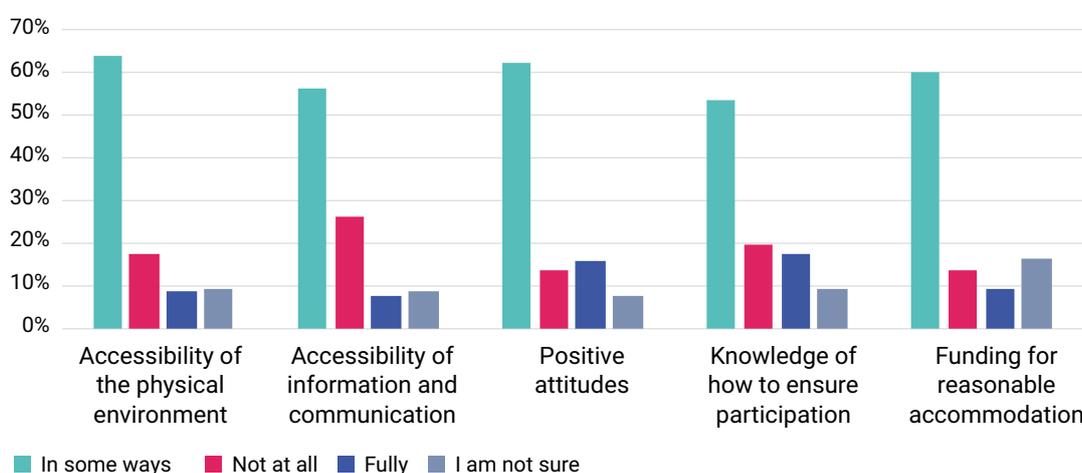
Participation of OPDs in decision-making remains insufficient with regards to the standards set by Article 4.3 which relates to all groups, and all issues concerning persons with disabilities. OPDs who are consulted are primarily consulted on disability-specific issues, such as disability policies, and they are mostly funded through INGOs focused on disability, which indicates that disability is not yet considered a cross-cutting issue.

Invite persons with disabilities to participate even when the subject is not disability. We also want to talk about everything else. Disability is a cross-cutting issue. That's inclusion.

– Survey respondent from Brazil (about the UN).

Significant barriers to participation in decision-making remain, whether with governments, UN or funding agencies. Preconditions for participation are not met; such as accessibility of the physical environment, accessibility of information and communication; there remains poor attitudes and knowledge about how to engage with persons with disabilities and a lack of funding for reasonable accommodation.

Figure c – Preconditions for meaningful participation of persons with disabilities in the work of the government.



Financial support remains the biggest challenge for OPDs to exist as representative organisations, although 32% of OPDs reporting their funding increased or increased a lot as compared to one year ago. This strongly undermines their independence and autonomy and ability to develop their capacities and engage with others. As organisations representing discriminated groups, OPDs equally experience the consequences of prejudice and discrimination, resulting in lower levels of education, lower access to funding opportunities, and fewer invitations to participate compared to other civil society groups.

As the funding opportunities are small, many people cannot be always regularly involved in organizations and their management and administration, as they work and study in parallel, however they have commitment and motivation to contribute to the disability rights cause.

– Survey respondent from Georgia.

OPDs also report lacking the resources and technical and organisational capacity to engage. Because of the number, complexity and lack of coordination between different processes and stakeholders soliciting OPDs' inputs, OPDs face significant opportunity costs when choosing to engage with different agencies. This, combined with limited financial resources, and is experienced more harshly by underrepresented groups, and this results stretching OPDs' capacities to the maximum.

Generally, DPOs especially in developing countries have very weak capacity to engage the supply side. It is very important that resources be invested in building the capacities of DPOs, through series of trainings and exchange programme so they are better equipped to drive the needed change. Strengthened DPOs, especially institutionally for DPOs to be able to develop systems and structures to run well equipped offices or Secretariat to administratively drive and deliver the needed change.

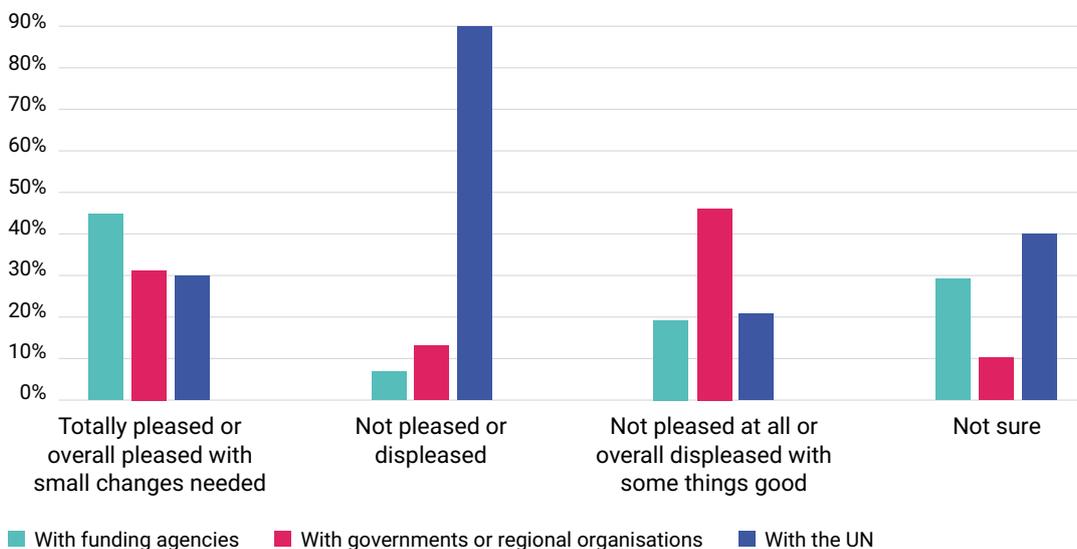
– Survey respondent from Nigeria.

It's important to work on capacity building and make the participation of the civil society meaningful through easy-to-understand ways of participation. Everything that's too technical won't be accessible to mostly part of the population. Especially in developing countries. But the people themselves are the only ones who really understand their contexts and without their participation it's impossible to make CRPD or SDGs a reality.

– Survey respondent from Brazil.

OPDs get involved with but are not satisfied with their level of participation with their government. Levels of information and opportunity to influence are inadequate, with very few respondents indicating having significant roles in co-decision making; the majority of OPDs report that while they are indirectly aware of civil society activities, they are often not directly informed about them.

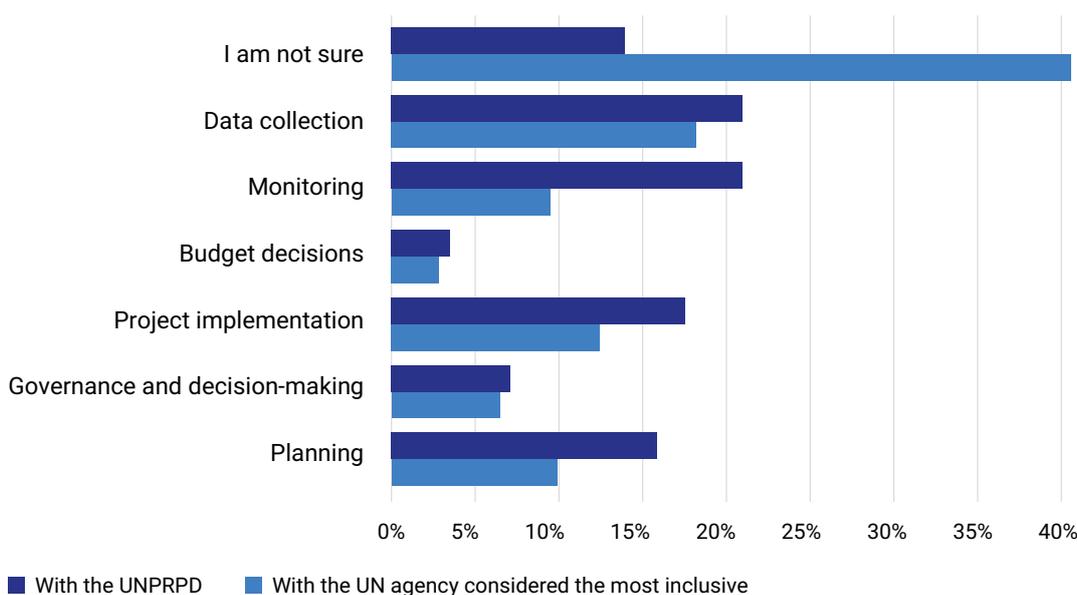
Figure d– Satisfaction of OPD respondents with their engagement with government, UN and funding agencies (% of respondents).



At the level of international cooperation stakeholders, OPDs are less often involved and less familiar with the United Nations than they should be. When they do engage, experiences are mostly positive, with the UNPRPD perceived as more inclusive of OPDs across the programme cycle than other UN programmes or entities.

OPDs engaged with funding agencies report positive experiences, enabling them access to funding and technical guidance, for instance, to facilitate policy change. Increasing financial resources to OPDs tends to be associated with greater involvement of OPD.

Figure e – Stages of the programme cycle at which OPDs are involved with the UN entity they consider the most inclusive and with the UNPRPD.

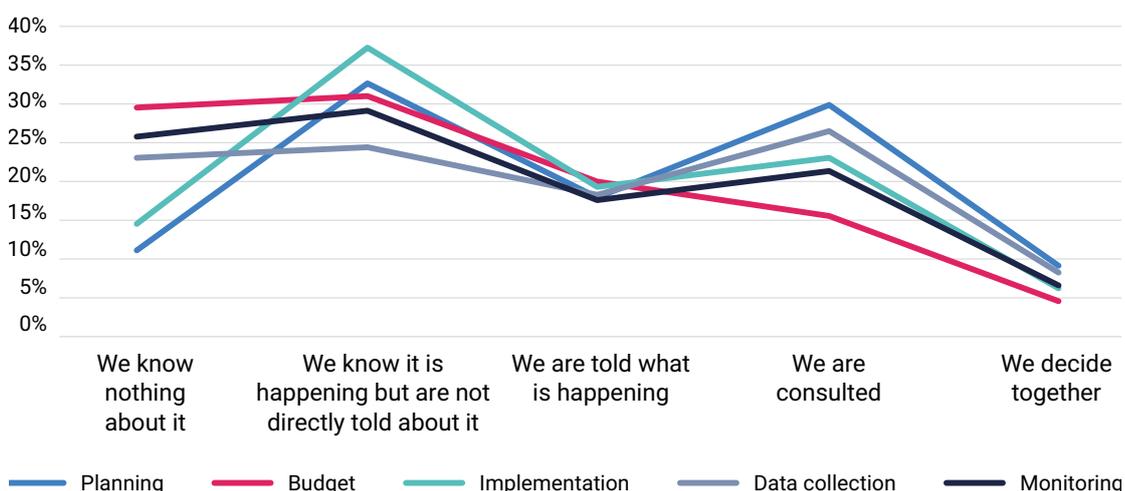


While there is evidence for the increasing engagement of OPDs, their contributions are not yet adequately being taken into account. OPDs have a critical contribution to make and their participation can contribute to meaningful changes, including improvements in inclusive policy and legislation, greater accessibility, improved access to services and awareness of the rights of persons with disabilities. OPDs continue to report negative experiences regarding their participation, such as being denied reasonable accommodation or partial accessibility resulting in exclusion, co-optation

Some Ministries are very responsive in mainstreaming the issues of persons with disabilities while others lack the technical capacity to understand issues of disability. Sometimes DPOs are invited on tokenism which hinders their full and effective participation in both policy and programmatic reform processes for example you can be invited for a law reform process only for the document to be circulated the night before: this means DPOs cannot effectively contribute to that particular process.

— Survey respondent from Kenya.

Figure f – Level of shared decision-making of OPDs with government, by stage of the policy/ programme cycle.



IDA's recommendations for meaningful participation of OPDs

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, and enables their regular and effective engagement, by ensuring equal opportunities to contribute to decision-making.

Meaningful participation is part and parcel of a shift in how disability and persons with disabilities are effectively viewed and considered: from being recipients without a say (information receivers), OPDs are progressively being heard (informers, through consultation). While there are indicators of overall positive trends towards more participation of OPDs, much remains to be done.

Meaningful participation as expected from OPDs is participation that seeks the highest levels of shared decision-making on all issues that concerns persons with disabilities, whether for domestic issues, through international cooperation or in situations of risk and humanitarian emergencies.

Meaningful participation is not only about the scope, extent and quantity of participation, but also about quality of participation and of the conditions for participation. These include measures to equalize opportunities for persons with disabilities to contribute, through accessibility and the provision of reasonable accommodation. But they also include efforts to create an environment that is conducive to effective contribution. Indeed, "OPDs have limited resources, and meaningful engagement in any process generates strong opportunity costs in terms of time and human resources"¹. **As opportunities to engage are growing, support is needed to equip OPDs with the resources (including skills, information, insights, data and evidence) in order to prioritize, identify key windows of opportunity for influence and strategize their inputs for more impact.**

Drawing from the findings of the survey and respondents' recommendations, complemented by IDA's own experience of engagement as a global OPD network as well as recent studies, the report provides recommendations to governments, the UN and funding agencies to ensure effective and meaningful participation of persons with disabilities in their work:

1 Cote, A. and al (2020). [The unsteady path towards meaningful participation of persons with disabilities](#), Bridge the Gap program.

+ Recommendations to governments

- 1. Repeal all laws that prevent persons with disabilities from being considered citizens with equal rights** and from being closely consulted and actively involved. This includes repealing, in particular, laws denying legal capacity to persons with all types of disabilities – including intellectual and psychosocial disabilities.
- 2. Create a policy framework and political environment that enables the functioning of OPDs as civil society organisations representing the diversity of persons with disabilities**, supporting their autonomy and capacity to operate in the longer run.
- 3. Ensure that OPDs have access to adequate funding mechanisms**, including through public funding and international cooperation. Facilitate their access by ensuring application processes and requirements are accessible and proportionate to the realities of the different size and capacity of OPDs.
- 4. Ensure that OPDs can access technical support**, capacity building and opportunities to develop their skills as credible interlocutors of decision-making.
- 5. Adopt a policy framework that recognizes the right to participation** and involvement of organisations of persons with disabilities with **clear procedures for consultations at all levels of decision-making** (from local to national), **all stages** (from planning to evaluation) **and on all issues** relevant to persons with disabilities; including international cooperation issues and situations of risk and humanitarian emergency.
- 6. Enable and respect the unique role of OPDs:** Provide information in advance, in accessible formats, and provide realistic timelines so that OPDs have equal opportunities to prepare, consult and contribute. Give consideration to OPDs' inputs as best placed to propose or confirm the relevance of proposed policies and programmes to persons with disabilities.
- 7. Ensure accessibility of all consultations** and the provision of reasonable accommodation to representatives of OPDs taking part in consultations, including accessible venues or teleconference technologies, accessible information and communication, including captioning, national sign languages and understandable formats, accessible, open and transparent procedures.
- 8. Guarantee and support the meaningful participation of the diversity of persons with disabilities through OPDs**, including women with disabilities, children with disabilities (including through age-appropriate assistance), indigenous persons with disabilities, persons with deafblindness, persons with intellectual disabilities and persons with psychosocial disabilities, and other underrepresented groups within their contexts.
- 9. Hire persons with disabilities and train government staff on the rights of persons with disabilities** and how to engage with persons with disabilities in ways that respect and pay consideration to their preferred ways of engagement, and their opinions and unique expertise as persons with a lived experience of disability. Mobilise OPDs as trainers.
- 10. Develop and implement mechanisms for the monitoring of States' compliance with the CRPD**, including Articles 4.3 and 33.3, and facilitate a leading role for OPDs in such monitoring.

+ Recommendations to the United Nations

- 1. Act as allies of OPDs to facilitate their strategic engagement with governments:** Bridge information gaps, facilitate OPDs' access to data and evidence (e.g. inclusive situational analysis, use of statistical and administrative data, budget information), provide overall information on upcoming policy reform and major projects and opportunities to engage, promote dialogue and access to decision-making processes.
- 2. Support OPDs to strategize their contributions, model by example through support effective and empowering OPD participation:** Engage with OPDs in ways that support movement building. Support the development of common advocacy platforms including underrepresented groups and women and girls with disabilities. Coordinate across stakeholders to streamline consultations with OPDs where relevant, respecting their priorities and reducing contradictory or overwhelming demands.
- 3. Inform OPDs about the work of the UN:** proactively reach out to OPDs, allocate time and resources to meet and understand the work and priorities of OPDs, including at the local level. Establish a dialogue and share regular information about the UN and their work in accessible formats. Where relevant, develop direct partnerships with OPDs, including clear roles in projects and programmes, provision of expertise in awareness-raising and training. Focus on long-term cooperation, as it yields better results than short-term projects .
- 4. Actively support the implementation of the UN Disability Inclusion Strategy (UNDIS),** through the adoption by each UN entity of a policy that actively supports participation and involvement of organisations of persons with disabilities and clear procedures for consultations at all levels of decision-making (from local to national), all stages (from planning to evaluation) and on all issues relevant to persons with disabilities, including in situations of risk and humanitarian emergencies.
- 5. Ensure accessibility of all consultations organised by the UN** and the provision of reasonable accommodation to representatives of OPDs taking part in consultations, including accessible venues or teleconference technologies, accessible information and communication including captioning, national sign languages and understandable formats, accessible, open and transparent procedures.
- 6. Ensure OPDs have access to funding opportunities,** including through direct funding from UN agencies and programmes. Facilitate their access by ensuring application processes and requirements are accessible and proportionate to the realities of different size and capacity of OPDs. Make budgetary provisions for involvement of OPDs in consultation and meaningful participation of projects, including accessibility and reasonable accommodation. Where relevant, condition UN funding to projects that entail clearly resourced OPD participation in projects.
- 7. Hire persons with disabilities and train UN staff on the rights of persons with disabilities** and how to engage with persons with disabilities in ways that respect and pay consideration to their preferred ways of engagement, and their opinions and unique expertise as persons with a lived experience of disability. Mobilise OPDs as trainers.
- 8. Guarantee and support the meaningful participation of the diversity of persons with disabilities through OPDs,** including women with disabilities, children with disabilities (including through age-appropriate assistance), indigenous persons with disabilities, persons with deafblindness, persons with intellectual disabilities and persons with psychosocial disabilities, and other underrepresented groups depending on contexts.
- 9. Monitor and account for progress under indicator 5 of the UNDIS ,** and share learning and good practices to advance its enforcement across the whole UN system.

+ Recommendations to funding agencies

1. **Enhance funding to support OPDs' organisational and technical development**, as a key component to ensure they have the resources to perform their role with independence, autonomy and capacity. Facilitate theiden, explore partnerships and fiscal sponsorship with larger OPDs to redistribute to their members.
2. **Ensure that funding does not discriminate against persons with disabilities and actively contributes to advancing their human rights.** Require as one of the conditions for funding to projects that they entail clearly resourced OPD participation. Ensure budgetary provisions for involvement of OPDs regarding consultation and meaningful participation in projects, including budgets available for accessibility and reasonable accommodation.
3. **Engage regularly with OPDs as allies to support inclusive, relevant and sustainable international cooperation investments:** proactively reach out to OPDs, allocate time and resources to meet and understand the work and priorities of OPDs, including at the local level. Provide information on donor priorities and strategies for technical assistance to governments, upcoming policy reform, major projects and opportunities to engage. Establish and maintain a regular dialogue, for example through annual consultations, to ensure inclusion of OPDs' priorities in donor strategies.
4. **Establish clear policy and procedures for consultations with OPDs** on all issues relevant to persons with disabilities, including in situations of risk and humanitarian emergencies. For bilateral donors, consult with OPDs from both the donor country and the recipient country. Coordinate across stakeholders to streamline consultations with OPDs where relevant, respecting their priorities and reducing contradictory or overwhelming demands.
5. **Ensure accessibility of all consultations** and the provision of reasonable accommodation to representatives of OPDs taking part in consultations, including accessible venues or teleconference technologies, accessible information and communication including captioning, national sign languages and understandable formats, accessible, open and transparent procedures.
6. **Establish or support participatory grant-making approaches** . OPDs should be included in decision-making about funding, including strategies and criteria behind funding, to ensure the relevance of funding to persons with disabilities. Seek feedback from and be accountable to OPDs, as one way of improving impact.
7. **Hire persons with disabilities and train funding agency staff on the rights of persons with disabilities** and how to engage with persons with disabilities in ways that respect and pay consideration to their preferred ways of engagement, and their opinions and unique expertise as persons with a lived experience of disability. Mobilise OPDs as trainers.
8. **Guarantee and support the participation of the diversity of persons with disabilities through OPDs**, including women with disabilities, children with disabilities (including through age-appropriate assistance), indigenous persons with disabilities, persons with deafblindness, persons with intellectual disabilities and persons with psychosocial disabilities, and other underrepresented groups depending on contexts.
9. **Monitor the share of funding that is effectively dedicated to inclusion of persons with disabilities**, using the OECD DAC marker for the inclusion and empowerment of persons with disabilities.
10. **Engage with the Global Action on Disability (GLAD) network to learn and share good practices** about effective ways of engaging with OPDs in donors' work.