Increasingly Consulted, but not yet Participating

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

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Foreword by the President of IDA

Dear reader,

The report you hold in your hands, read on your screen, listen to on your tablet, or watch in video format, provides an important message from the disability rights movement. If you are yourself a representative of an organisation of persons with disabilities (OPD), this report maybe includes your direct contribution. It speaks about the experience of persons with disabilities around the world of being included or not in decisions that affect our lives, the decisions on the inclusion of persons with disabilities in development programs and policies. **It provides insights from OPDs about how the 'Nothing about us without us' motto is experienced by the diversity of persons with disabilities**.

This report presents the findings of the first-ever global survey led by OPDs on their participation in decision-making. It is the first attempt of this scale to monitor how Article 4.3 and Article 32 of the Convention on the Rights of Persons with Disabilities (CRPD) is turned into action. Article 4.3 was a major ask from the disability rights movement and sets an obligation for States to closely consult and actively engage with persons with disabilities, through their representative organisations, in all decisions that concern them. Article 32 lays out obligations to ensure that international cooperation, including development programmes and humanitarian aid, is inclusive of and accessible to persons with disabilities.

To this end, **OPDs have a critical role to play**. But they need to have the resources and opportunities to participate. Decision-makers, including governments, the United Nations and funding agencies, need to show willingness and create the conditions for this meaningful participation. This IDA Global Survey was an attempt to collect, analyse and better understand how OPDs experience and perceive the scope, quality, strength and influence of their participation.
This report shows that, **while disability is increasingly mentioned in the development agenda and OPDs are increasingly invited, our contributions are not yet considered, and much progress remains to be done**. Learning from OPDs' views, this report draws recommendations to enhance the meaningful participation of all persons with disabilities through OPDs at all levels.

It is our hope as IDA that this first report can serve as a baseline, to monitor progress in realising Article 4.3 of the CRPD. We also hope that it will **inform and guide States, the UN system and funding agencies, as well as OPDs themselves, to better engage in effective collaborations towards the realisation of all human rights for all persons with disabilities**. At the time of finalising this report, the Covid-19 hits the world and is disproportionately impacting persons with disabilities. While adapting to the pandemic, OPDs are as ever the best placed to recommend what works or not for them, to build back better and more inclusive societies.

IDA wishes to warmly thank all contributors to this Global Survey, especially respondents from OPDs, IDA members, their members and beyond, who took interest and dedicated time to respond to this survey. Our recognition and appreciation also go to their tireless efforts, as OPDs, to advance the rights of persons with disabilities by bringing their unique views and expertise to ensure they inform decision-making processes.
Nothing about us without us!

Ana Lucia Arellano,
President of the International Disability Alliance

Acknowledgements

Executive Summary

Background: a global momentum towards 'disability inclusion'

Participation of citizens is a fundamental principle of democratic societies. It supports good governance and social accountability[1], 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 (OPDs[2]) 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.

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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.

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 programmes[3]. 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.

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?

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3   CRPD/C/GC/7 para 8.

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.

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.

- **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.

- **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.

- **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.

- **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.

- **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.
- **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.
- 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.
- **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 or being invited to legitimize a process, without their view being adequately considered.

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"[4]. **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: **Recommendations to governments**: repeal all laws that prevent persons with disabilities from being considered citizens with equal rights; create a policy framework and political environment that enables the functioning of OPDs as CSOs; ensure that OPDs have access to adequate funding mechanism and technical support; adopt a policy framework that recognizes the right to participation of OPDs with clear procedures for consultations at all decisions of decision-making and on all issues; enable and respect the unique role of OPDs; ensure accessibility of all consultations; guarantee and support the participation of the diversity of persons with disabilities through OPDs including underrepresented groups; hire persons with disabilities and train government staff on the rights of persons with disabilities; and develop and implement mechanisms for the monitoring of States' compliance with the CRPD.

Recommendations to the United Nations: act as allies of OPDs to facilitate their strategic engagement with governments; support OPDs to strategize their contributions, model by example through support effective and empowering OPD participation; inform OPDs about the work of the UN; actively support the implementation of the UN Disability Inclusion Strategy (UNDIS); ensure accessibility of all consultations organised by the UN; ensure OPDs have access to funding opportunities; hire persons with disabilities and train UN staff on the rights of persons with disabilities; guarantee and support the participation of the diversity of persons with disabilities through OPDs; and monitor and account for progress under indicator 5 of the UNDIS.

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

Recommendations to funding agencies: enhance funding to support OPDs' organisational and technical development; ensure that funding does not discriminate against persons with disabilities and actively contributes to advancing their human rights; engage regularly with OPDs as allies to support inclusive, relevant and sustainable international cooperation investments; 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; ensure accessibility of all consultations; establish or support participatory grant-making approaches; hire persons with disabilities and train funding agency staff on the rights of persons with disabilities; guarantee and support the participation of the diversity of persons with disabilities through OPDs, including underrepresented groups; monitor the share of funding that is effectively dedicated to inclusion of persons with disabilities and 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.

1 Why participation of persons with disabilities matters

Participation is key to the advancement of all human rights

A human right, too often denied to persons with disabilities

Participation of citizens is a fundamental principle of democratic societies. It supports good governance and social accountability[5], by allowing people to influence and exert control over decisions that affect their lives.

Participation in public life is recognized as a human right in Article 21 of the Universal Declaration of Human Rights and reaffirmed in Article 25 of the International Covenant on Civil and Political Rights, as well as numerous other human rights treaties[6]. A human rights-based approach to public decision-making requires the active and informed participation of everyone in decisions that affect their lives[7].

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. Among others, persons with intellectual disabilities and persons with psychosocial disabilities are particularly affected by stigma and denied equal recognition before the law and the capacity to meaningfully contribute to their community and societies. **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.**

Participation of persons with disabilities is at the heart of the CRPD

This entrenched discrimination affecting all areas of life called for an urgent recognition and reaffirmation of the human rights of all persons with disabilities. 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.

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5   A/HRC/31/62, para. 13.

6   Under article 5 (c) of the International Convention on the Elimination of All Forms of Racial Discrimination, article 7 of the Convention on the Elimination of All Forms of Discrimination against Women, and articles 12 and 23 (1) of the Convention on the Rights of the Child

7   Office of the United Nations High Commissioner for Human Rights (2006). Principles and Guidelines for a Human Rights Approach to Poverty Reduction Strategies. HR/PUB/06/12

Recognition that persons with disabilities face "barriers that hinder their full and effective participation in society on an equal basis with others" is part of the purpose of the CRPD (Article 1). Participation is general principle (Article 3) which means it underpins all of the CRPD, and an explicit general obligation (Article 4.3). Participation in society on an equal basis with others is an outcome pursued by the CRPD; achieving this outcome also requires participation as a process, i.e. through consultation, active involvement and engagement of persons with disabilities at all levels.

Participation of persons with disabilities is acknowledged as leading to positive impact on decision-making processes. It ensures that the knowledge and life experiences of persons with disabilities are considered when deciding upon new legislative, administrative and other measures[8]. It ensures that measures that can advance or hinder their rights are identified and discussed, leading to greater effectiveness and equal use of public resources.
Eventually, participation can also be a tool for social change, as the involvement of organisations of persons with disabilities strengthens their capacity to understand policy processes, to advocate and negotiate for their rights, and to encourage their capacity to represent diversity with a unified voice. As suggested by Löve et al. "to change their position of oppression, marginalised groups must be a part of the political structure, engage in setting the agenda and defining the issues, and redefining the concepts that relate to their lives"[9].

Article 4.3: 'Nothing about us without us' becomes a legal obligation

CRPD, Article 4.3 – General obligations
States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake: (…)
3. 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.

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.
The CRPD Committee General Comment 7 reaffirms the wide scope of Article 4.3, covering legal and regulatory frameworks and procedures across all levels and branches of government, access to public decision-making spaces and other areas of research, universal design, partnerships, delegated power and citizen control[10]. It all stresses the importance of ensuring that the wide diversity of persons with disabilities are represented in consultations.

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8   CRPD/C/GC/7, para. 18, page 5
9   Löve, L., Traustadóttir, R., Quinn, G., Rice, J. (2017). The inclusion of the lived experience of disability in policymaking. Laws, MDPI, Open Access Journal.
10   CRPD/C/GC/7, para. 15, 17

General Comment 7 also recalls that the right to participate is a civil and political right and an obligation of immediate application, not subject to any form of budgetary restriction[11]. It insists on participation being meaningful, with reasonable timelines, and with information on the outcomes of consultations. It should be supported by allocations to cover the related expenditures, by information available in accessible formats, and consultations held in accessible venues, with facilitation for the participation of the wide diversity of persons with disabilities, including reasonable accommodation. Through Article 4.3, persons with disabilities thus have a clear and unique provision supporting their involvement in decision-making.

The role of Organisations of Persons with Disabilities (OPDs)

Intermediary bodies to represent persons with disabilities

The CRPD stresses the importance of organisations of persons with disabilities (OPDs) as representative organisations. OPDs are a specific type of civil society organization and should be distinguished from others, such as organisation for persons with disabilities. Organisations of persons with disabilities are only those that are led, directed and governed by persons with disabilities[12], and bring a unique perspective to speak on their own behalf. OPDs actually play diverse roles as civils society organisations, from voicing the concerns of persons with disabilities, to providing peer support, facilitating access to information and services (sometimes even delivering services),

providing technical guidance on disability or acting as watchdogs on the rights of persons with disabilities. OPDs have different strategies in different contexts, which also impact how they are structured, organized and how they develop. They play a critical role in supporting participation of persons with disabilities in public life, representing and conveying the perspective of their constituencies. "In substance, **the CRPD clearly establishes OPDs as intermediary bodies between policy makers and persons with disabilities"[13].** As such, OPDs are a key component of a diverse civil society and an important contributor to democracy. 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 government 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[14].

In their role to fund, technically support and guide development, peace and democracy, funding agencies and the United Nations have an important responsibility to also engage with OPDs. The level of priority they give to disability and OPD engagement in their assistance programmes, methods and funding modalities can have a significant impact on public participation processes, as well as the possibility for OPDs to develop as stronger civil society counterparts.

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11   CRPD/C/GC/7, para. 28

12   CRPD/C/GC/7, para. 11, page 4

13   The Unsteady Path https://bridgingthegap-project.eu/wp-content/uploads/The-unsteady-path.-A-pilot-study-by-BtG.pdf

14   ibid.

Responsibility and power dynamics

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, to articulate demands strategically (e.g. technically sound, evidence-based and in compliance with the CRPD), and to maintain independence. These are key concerns that guide IDA's action as an alliance of OPDs, representing 1 billion persons with disabilities through global advocacy. Effective representation requires consideration of the prevailing conditions, including the history of discrimination and prejudice towards persons with disabilities and OPDs. They are comparatively newer civil society organisations, who lack support and opportunities to engage. "It is undeniable that having experienced long-term exclusion and lack of support and opportunities for social interaction and community participation, persons with disabilities are (…) less likely to exert their citizenship as compared to the non-disabled"[15].

In other words, **while acknowledging the need for OPDs to constantly strive for the quality of representation, the burden of proof should not be reversed: participation as a right should be ensured in ways that seek to consolidate, rather than challenge, the roles and leadership of OPDs**. Setting unfair expectations or conditions to OPD participation would defeat the purpose and result in discrimination. Failing to remove barriers to participation, for example by denying reasonable accommodation, by not changing complex mechanisms or inaccessible venues, is also discriminatory[16].

Progress in realising Article 4.3

Some progress at the global level

The adoption of the CRPD has brought about major changes in how persons with disabilities are viewed and considered in societies. Their recognition by law as subjects of all human rights and fundamental freedom is progressively transforming how governments and other decision-makers at local, national and global levels include their perspective into laws, policies, programmes and services that impact all aspects of life. Twelve years after the entry into force of the CRPD, the CRPD Committee noted progress in implementation of the provisions of Article 4.3 and 33.3 by States, such as the consultation of organisations of persons with disabilities in mechanisms to monitor the CRPD[17].

At the global level, IDA, its members and partners played a major role in securing new space for representation of persons with disabilities in decision-making: through the Stakeholder Group of Persons with Disabilities on the SDGs (SGPWD), the Civil Society Forum to the Conference of State Parties to the CRPD and its coordination mechanism (CSCF), through a space for OPDs in the governance of the UN Partnership for the Rights of Persons with Disabilities (UNPRPD), as co-chair of the Global Action on Disability (GLAD) network, as co-chair of the Inter-Agency Standing Committee Reference Group on inclusion of persons with disabilities in humanitarian action, as co-host of the first Global Disability Summit held by the UK Government in 2018, or through creating space for interaction of OPDs with the UN Security Council on the situation of persons with disabilities in armed conflicts.

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15 As per Young, 2016, referred to by Cote, A. and al (2020). The unsteady path towards meaningful participation of persons with disabilities, Bridge the Gap program.

16 CRPD, Article 5

17 CRPD/C/GC/7 para 7

Linked to this engagement, major progress have been made in securing references to persons with disabilities in the 2030 Agenda, ensuring growing references to persons with disabilities in Voluntary National Reviews, developing an OECD DAC disability policy marker, generating a set of 968 commitments from a range of 170 world leaders through the Global Disability Summit 2018[18], getting endorsement from the IASC on Guidelines for inclusion of persons with disabilities in humanitarian action, to name a few.

At the regional level, OPD networks such as the European Disability Forum (EDF), the Pacific Disability Forum (PDF) or the ASEAN Disability Forum (AsDF) are getting increasingly recognized as interlocutors of regional intergovernmental bodies, and have been influencing significantly regional policy frameworks[19].

Success means that the discourse shifted from whether to include persons with disabilities to how to include. This is experienced by IDA through a growing number, diversity, scope and technicity of requests for contributions from OPDs, stretching capacities to the maximum.

Meaningful engagement of persons with disabilities in policies and programmes is the responsibility of all and is yet to be seen

Despite unprecedented progress and momentum at the global level, meaningful engagement of persons with disabilities is still largely insufficient. In 2018, the CRPD Committee pointed to significant gaps 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 programmes**[20]. While progress have been made over the last decade in particular with regards to creation of formal national mechanisms, there is not, in most countries, an enabling environment that would allow meaningful participation of OPDs, especially women with disabilities and most marginalised groups. Those formal mechanisms are often under-resourced, lack transparency, and seem to have limited impact on sectoral policy making processes that impact persons with disabilities[21]. Article 4.3 not only applies to participation in domestic programmes and policies but also to international cooperation, as recalled in Article 32 of the CRPD. **In low and middle-income countries, where aid may represent a significant contribution to development efforts, international cooperation should also ensure participation of OPDs and support their capacity to play their role as civil society counterparts**. Bilateral funding agencies, as well as private funding agencies registered in countries that have ratified the CRPD are hence equally concerned and should ensure participation of persons with disabilities. As recently shown by Development Initiatives, aid projects targeting persons with disabilities made up less than 2% of all international aid between 2014 and 2018, and only 9% (US$360 million) of DAC-marked aid in 2018 was clearly described for the purpose of disability-inclusion[22]. This suggests that OPDs are largely excluded from either shaping international aid priorities, and therefore less likely to benefit from and take part in their implementation.

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18 74% of these commitments are under way one year after the Summit, as accounted for in: Global Disability Summit, One Year On report, Sep. 2019, report produced by Equal International for DFID, IDA and Government of Kenya.

19 For example, PDF played a strong role in shaping the Pacific Framework on the Rights of Persons with Disabilities 2016-2025; following the European Disability Strategy 2010-2020, EDF is actively involved in advocating for a comprehensive European Disability Rights Agenda 2020-2030; the ASEAN Disability Forum influenced the ASEAN Enabling Master Plan 2025 on mainstreaming the rights of persons with disabilities.

20 CRPD/C/GC/7 para 8.

21 Cote, A. and al (2020). The unsteady path towards meaningful participation of persons with disabilities. Bridging the Gap Project.

22 Walton, D. (2020). Disability-inclusive ODA: aid data on donors, channels, recipients. Development Initiatives. See also: How well is aid targeting disability?, Development Initiative as part of the Inclusive Futures programme, Dec. 2019.

At the UN level, ground-breaking commitments have been made in 2019 with the adoption of the first-ever systematic instrument to systematize disability mainstreaming across the UN system. **The UN Disability Inclusion Strategy and its accountability framework indeed set ambitious milestones, including for "systematic close consultation with and active involvement of, organizations of persons with disabilities on all disability-specific issues and broader issues" (indicator 5)**[23]. The UNDIS fully clarifies the responsibility of the UN system in contributing to the realisation of the CRPD, including through ensuring active involvement of OPDs.

Why it is essential to monitor participation of persons with disabilities

Growing attention to disability: a risk of 'more of the bad things'

As the global momentum rises and more commitments are made towards disability inclusion, **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**. Social innovation, willingness and readiness of mainstream systems and actors to change is yet to consolidate and requires training programmes and sharing of good practices with government staffs, development practitioners, the UN and OPDs alike.

Participation of persons with disabilities, through their representative organisations, is essential to guide reforms and transformations.

Enhanced attention to disability that is not guided by the knowledge and priorities of persons with disabilities themselves may well result in 'more of the bad things' that have been detrimental to persons with disabilities' rights.

For example, governments willing to reflect their action towards persons with disabilities in education may invest into more special schools leading to further isolation of children with disabilities. IDA also observes that the high priority given to mental health paves the way to addressing issues faced by persons with psychosocial disabilities mostly through a health entry point and medical approach that contradicts a right-based model and may undermine the right to be included in the community[24]. The growing agenda on mental health and expanding services leads to little consideration to the social determinants of health (e.g. poverty, pressure) and deprioritising access to justice, decent work, housing, social protection etc.

The IDA Global Survey: evidence for accountability

Against this background, IDA felt the acute need to equip itself with tools to collect evidence and analyse the reality of OPD's engagement. Therefore, the IDA Global Survey was conceived as a way 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.

This first IDA Global Survey aims to establish a baseline. By conducting the survey every two years, IDA intends to develop it as a regular tool to measure progress, learn from what works, know where to improve, to strategize advocacy and support ongoing efforts.

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23 [UN Disability Inclusion Strategy](#) (2019).

24 UN Human Rights Council, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/HRC/35/21 (2017), and [A/HRC/44/48](#) (2020).

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 organisations of persons with disabilities. As such, the Global Survey is meant to become a regular instrument for the monitoring of CRPD Article 4.3, based on evidence of trends, barriers and facilitators. It is hoped that the Global Survey results can inform continuous efforts of governments, the UN or funding agencies towards improving participatory practices.

It is also meant to provide IDA as a global network representing the voices of persons with disabilities with stronger evidence on the reality of participation as experienced by representative organisations from local to regional levels. This will support the disability rights movement to constantly re-question its role and efforts to represent the diversity of persons with disabilities at all levels. As such, the Global Survey can be a source of learning to identify where and how to focus IDA's advocacy and capacity development efforts.

2 About the IDA Global Survey

Scope of the survey

Organisations of persons with disabilities

The IDA Global Survey aimed to capture information about participation of persons with disabilities in programmes and policies through the opinion of their representative organisations. It intended to capture one response per organisation, respondents being members, staff, or board members of the concerned organisation. Organisations that are members of broader umbrella federations or networks were invited to respond independently.

The introduction to the questionnaire defined that for the scope of the survey, "a Disabled Persons Organisation (OPD) is any organisations or association that is governed by persons with disabilities". General Comment 7 extensively describes the nature and diversity of organisations of persons with disabilities, including umbrella and coalition organisations, single-disability organisations, formal or informal organisations, organisations including family members and/or relatives of persons with disabilities, self-advocacy groups, organisations of women with disabilities or of children and youth with disabilities, among others. The Survey was disseminated globally with initial expectations that responses from at least 50 countries would be required as reliable minimum geographical outreach.

Programmes and policies led by governments, the United Nations and funding agencies

The IDA Global Survey covers a wide range of decision-making mechanisms that have a large impact on populations. 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.
- Programmes of action and projects supporting the realisation of policies and strategies
- The application of the above in all areas: disability-specific and non-disability specific policies and programmes
- Policies and programmes at local, national and regional levels (including implementation of global policies and programmes at these levels
- Formal and informal ways of consulting and engaging with civil society in decisions-making.

What we understand by participation of OPDs

This survey does not attempt to define a conceptual framework for participation of persons with disabilities in decision-making. It complements the recent study realised by the Bridging the Gap project[25], which analyses the outcome of civil society participation in relation to the overall political context and the relationship between States and civil society, through the examples of 5 countries. Acknowledging that "participation is a coproduction between state and the disability movement, (…) influenced by other actors such as service providers and international cooperation actors", the IDA Global Survey focuses on an analysis of the perceptions of OPDs of their experiences with the government, UN and funding agencies, i.e. on the experience of the relationship from the side of civil society.
As a quantitative survey, it does not allow to fully appreciate the two-way relationship between OPDs and decision-makers, however it provides interesting examples, from real citizen control to tokenistic participation.

This report analyses 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 simple information to full co-decision)?
- How effective: are the views of OPDs effectively considered?

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.

Methodology

Preliminary phase

The IDA Global Survey was developed in several stages. In early 2018, in the context of the Disability Catalyst Programme funded by DFID and co-funded by the Ministry of Foreign Affairs Finland, IDA launched a small-scale, fast-track consultation to assess the satisfaction of organisations of persons with disabilities with regards to their participation in programmes implemented by UN agencies under the UN Partnership on the Rights of Persons with disabilities (UNPRPD). A questionnaire was developed and administered through written responses or interviews with 13 respondents (from 13 countries out of the 25 countries covered by the UN PRPD at the time of the consultation). Though the sample was very small, this initiative enabled to test a first version of some questions pertaining to OPD participation with the UN.

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25   Cote, A. and al (2020). **The unsteady path towards meaningful participation of persons with disabilities. Bridging the Gap Project.**

The consultation found that about 60% of respondents (8 out of 13) indicated they were aware of the UNPRPD, of which 100% (8 said OPDs have been involved/ consulted in some way in the UNPRPD project. However, some groups were perceived by OPDs as less involved than others[26], and satisfaction with their engagement was contrasted[27].

Development and piloting

Building on this initial work, IDA developed terms of reference for a wider Global Survey, covering not only participation of organisations of persons with disabilities in UNPRPD projects but expanding the scope to government, United Nations and funding agencies programmes and policies. Similar questions were incorporated, yet the extended scope demanded significant changes, including adding skip options for respondents to select only their direct level of action (local, national, regional or global).

The comprehensive questionnaire was developed in English in May-June 2018, consolidated with the inputs of a reference group composed of members of the IDA Board in July 2018, and piloted online in August 2018 with members of the IDA Board, IDA Programme Committee, and the alumni of the Bridge CRPD-SDGs training initiative. A total of 49 respondents filled the survey and commented on readability and accessibility of the questionnaire and survey.

Consolidation, translation and dissemination of the questionnaire

Feedback was incorporated into a new version of the questionnaire, which was then converted into plain language (with the support of Inclusion International), tested with a group of self-advocates, and translated into other languages. Cognitive testing was ensured by native speakers familiar with English and disability rights, leading to adjustments in vocabulary and correction of errors.

The IDA Global Survey was administered as a voluntary, open-access, online-based questionnaire. The questionnaire was administered through the IDA website[28], and widely advertised through listservs such as the IDA_CRPD_Forum, the International Disability and Development Consortium, Bridge CRPD-SDGs list serves, as well as social media. Individual emails were sent to the members of IDA members (over 1000 organisations of persons with disabilities worldwide). Social media packages were available in different languages on the website to encourage visitors to the site to also disseminate the questionnaire with their members and partners.

The IDA post on the Global Survey quickly reached 5000 'likes' (by 12th December 2018) and reached over 13,000 people.

The questionnaire was launched on 3rd December 2018, which marked the International Day of Persons with disabilities, and remained open until 5th January 2019. While symbolically the date was a good way to draw attention from the disability rights movement, it is also an incredibly busy period, which may have impacted the response rate. The full questionnaire is available in Annex 1.

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26 While there is overall good involvement of women with disabilities, persons with deaf-blindness, persons with psychosocial disabilities, persons with intellectual disabilities and indigenous persons with disabilities are much less involved.

27 This fast-track consultation provides a contrasted picture of OPDs' satisfaction with their engagement in UNPRPD projects. On the overall satisfaction, respondents are shared between a half estimating that 'some practices are satisfactory, but there is a need to significantly improve', and another half being overall satisfied or more (25% are either very satisfied or totally satisfied).

28 www.internationaldisabilityalliance.org/global-survey

Data analysis

Two research assistants conducted preliminary cleaning of the data. The questionnaire was vetted[29] and data analysis was supported by a research team at the ALL (Assisting Living and Learning) Institute at Maynooth University, Ireland; each researcher had worked in the area of disability research and policy across low-, middle-, and high-income contexts for more than 5 years, up to over 25 years.

The preliminary report was released in June 2019 during the Conference of State Parties to the CRPD (COSP), accounting for direct findings from the survey closed questions. This report is an augmented version which captures further analysis and consolidated results. The survey data was further analysed to reveal trends in OPDs participation. Open-ended questions were thematically analysed to provide rich, in-depth dive in the trends uncovered. The qualitative data from the open-ended questions was analysed by coding for themes and codebooks were created based on the emerging themes. The qualitative data analysis then underwent inter-coder reliability and once the sample check was completed, the data for each open-ended question was analysed thematically. The IDA Global Survey brings an extremely rich dataset enabling a wide range of analyses.

It is however to caution against extrapolating from this single study across representative organisations of persons with disabilities globally, as it is impossible to state that the respondents to this study form a representative sample of the wider range of organisations of persons with disabilities worldwide.

For example, responding to the online survey required internet access and knowledge of at least one of the 7 languages in which it was translated. One can also assume that interest in responding to a survey on participation may also be influenced by prior exposure of OPDs to public life, proximity to political space, access to higher education or social status.

Accessibility of the IDA Global Survey

Languages

The initial questionnaire in English was converted into plain language, and tested with a group of self-advocates (with the support of Inclusion International). Simple definitions of more complex terms were made available for words identified in bold letters in the questionnaire (see the word bank in Annex 2). The English plain language version was then translated into Arabic, Chinese, French, Russian, Spanish and International Sign. One limitation was that translators involved in cognitive testing were not experienced with plain language, leading to potential reintroduction of language complexity at the time of translation. Conversion of the questionnaire into plain language also increased substantially the length of the questionnaire, as several questions had to be divided into two or more simpler questions. This was commented by several respondents as too long, while many appreciated the clarity of language used.

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29 Ravitch, SM., Mittenfelner Carl, N. (2016). **Qualitative research: Bridging the conceptual, theoretical, and methodological.** Thousand Oaks, CA: Sage.

Online survey software

Following a comparative review of accessibility features, SurveyMonkey® was identified as the most appropriate online software for the IDA Global Survey, with particular consideration for accessibility to screen readers.

For blind or partially sighted respondents, feedback from the piloting phase was largely positive, although two respondents reported issues with the screen reader for several questions.

For deaf respondents, the World Federation of the Deaf recommended a response option in International Sign for open-ended questions. As SurveyMonkey® does allow for video questions but does not allow uploading of responses in video format, an alternative option for recording and sending responses to open-ended questions in International Sign was set up.

Alternative options for responding to the survey were discussed with IDA members and proposed in the survey dissemination package, such as gathering members of an organisation of persons with disabilities in a face to face meeting to discuss and agree collectively on the response (with one person filling online)[30].

Monitoring accessibility of the survey to all persons with disabilities

Accessibility of the Global Survey was tested during the pilot phase. Overall, within the limitation of the online survey format (which is not accessible to all persons with disabilities including people without access to internet), high levels of accessibility were ensured (within the limits of the available budget), following the terms of reference for the Global Survey accessibility proposed by the IDA Secretariat and validated by the Reasonable Accommodation Committee of IDA.

While the Global Survey collected responses per organisation of persons with disabilities, and not per person with a disability, additional 'opening

questions' collecting information on the person completing the questionnaire were included as a proxy to verify that no group of persons with disabilities was missed. This included a question on whether the person received support to fill in the questionnaire. The analysis of the population of individual respondents shows that a diverse range of persons with disabilities could access and complete the survey, with or without support. The development of such a wide-scope survey in accessible formats was a pioneer experience in many ways, nurtured by the diversity of the disability rights movement represented by IDA members and is an investment that IDA will learn from and use further in the future. This will require some adaptations, in particular relating to the online survey app and functionalities.

Survey respondents

The Global Survey received 573 individual responses. While the survey sought one respondent per OPD, in some cases more than one person from each OPD responded. While there are 350 organisations for which only one respondent replied, other organisations had more than one respondent. Recognising that different people within the same OPD may have different views, we included all of the responses received.

The questionnaire included 6 opening questions which characterized the population of respondents to allow us to assess the reach of the survey, including the range of its potential accessibility.   This information is however not used in the report to disaggregate data by identity of respondents.

While the IDA Global Survey provides the first survey of its kind and scale we do not claim that it is representative of OP Ds globally.

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30   For recommendations related to the online survey tool, please see Annex 5.

Language

Distribution of responses per language (Figure 1) shows an overwhelming number of responses to the survey in English (71.6%), followed by Spanish (9.2%), Russian (5.9%), French (5.1%), Arabic (4.7%), International Sign (2.6%) and Chinese (2.6%).

Figure 1 – Distribution of responses per language of the survey.
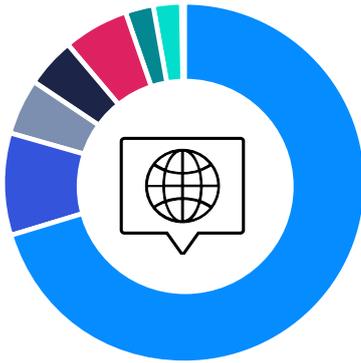
Numbers of responses:

- **English: 410**
- **Spanish:53**
- **Russian: 34**
- **French: 29**
- **Arabic: 27**
- **Chinese: 15**
- **International Sign: 15**

Age and gender

The average age of respondents was 45 (SD = 13.4). In Figure 2, the age distribution per age group shows similar percentages for age groups 31 to 40 (24%), 41 to 50 (26%), and 51 to 60 (22%), while only 15% of respondents are below 30. This may be explained by the intention to capture one response per organisation, which may have led to respondents being those in a representative function, often held by more senior people. Distribution of gender (Figure 3) shows a slightly higher proportion of men respondents (51.6%) as compared to women (47.4%) while 6 respondents (1.1%) identified as 'other'.

Figure 2 – Distribution of responses per age of respondents.
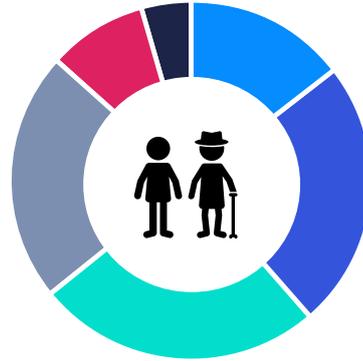
Percentage of respondents:

- **30 and under: 14,7%**
- **31-40: 24%**
- **41-50: 25,7%**
- **51-60 : 22,4%**
- **61-70: 9%**
- **71-88: 4,2%**

Figure 3 – Distribution of responses per gender.
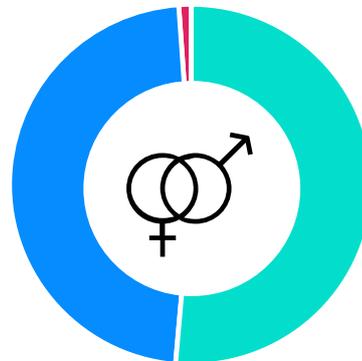
Numbers of respondents:

- **Men: 294**
- **Women: 270**
- **Other: 6**

Disability constituencies

Respondents were asked to self-identify as persons with or without disabilities and indicate their type of impairment. While methodology of disability measurement provides evidence that such a question typically misses people who do not self-identify as persons with disabilities, the assumption here was that members or representatives of organisations of persons with disabilities do easily self-identify, as their mandate is to represent this characteristic of human identity and diversity. As said above, data on individual respondents is not used any further to analyse the data collected through the survey.
Distribution as shown in Table 1 below reflects a higher proportion of respondents with physical impairments (29.8%), followed by persons without a disability (21.7%), while the lowest number of responses are from persons who self-identified as persons affected by leprosy or persons with a cognitive impairment (0.2% each).

Table 1 – Distribution of survey respondents (self-identified).

DISTRIBUTION OF SURVEY RESPONDENTS (SELF-IDENTIFIED)	NUMBER	%
Persons with physical impairments	169	29,8%
Blind or partially sighted persons	53	9,3%
Deaf persons	47	8,3%
Hard of hearing persons or persons with other hearing difficulties	31	5,5%
Persons with multiple impairments	16	2,8%
Persons with a psychosocial disability	15	2,6%
Persons with a chronic disease	13	2,3%
Persons with an intellectual disability	8	1,4%
Persons with autism	7	1,2%
Persons with deaf-blindness	6	1,1%
Persons of short stature	3	0,5%
Persons affected by leprosy	1	0,2%
Persons with a cognitive impairment	1	0,2%
Persons without a disability	123	21,7%
Other	74	13,1%

A total of 16.5% respondents reported receiving support from another person to complete the questionnaire. Finally, 105 (18.4%) respondents reported being Bridge CRPD-SDGs training alumni, while 466 (81.6%) reported not having passed through a Bridge cycle yet.

Characteristics of responding organisations of persons with disabilities

Countries in which organisations of persons with disabilities work

OPDs worked across 165 countries encompassing all continents, with the largest presence being reported in India (n = 68) for Asia; Kenya (n = 22) and Nigeria (n = 22) for Africa; Sweden (n = 16) for Europe; New Zealand (n = 47) in the Pacific; the United States (n = 11) in North America; and Colombia (n = 10) in South America. The complete list of countries in which the responding OPDs work can be found in Annex 3.

A total of 366 (78.9%) respondents reported that the UNCRPD was ratified in their country, while 39 (8.4%) reported that it was not, and 59 (12.7%) respondents were not sure.

In relation to the SDGs, in total 307 (67%) respondents reported that they were aware of any work or actions that their country's government had done on the SDGs, 71 (15.5%) reported that they were not, and 80 (17.5%) reported that they were not sure.

Regional distribution

A grouping of the above countries per region[31] indicates that OPD respondents to the survey work in the following regions (see Figure 4 below): 315 responses from organisations of persons with disabilities working in Europe, 281 in Africa, 215 in Asia, 48 in North America, 38 in South America, and 60 in Oceania.

Figure 4 – Regions in which OPD respondents work.

Legend figure 4:
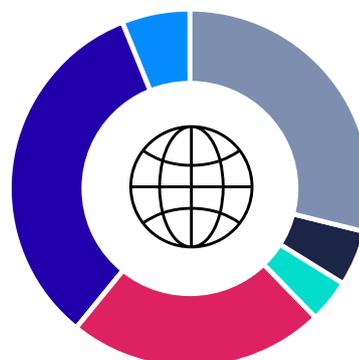
- **Europe 33%**
- **Africa 29%**
- **Asia 23%**
- **Oceania 6%**
- **North America 5%**
- **South America 4%**
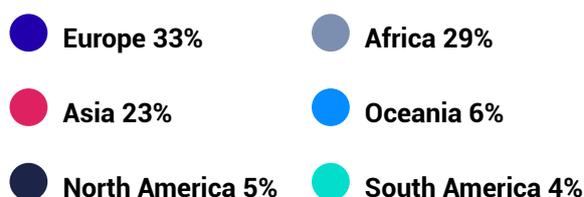
Table 2 – Regions in which OPD respondents work.

REGIONS	COUNTRIES	RESPONSES
Africa	53	281
North America	11	48
South America	11	38
Asia	35	215
Europe	47	315
Oceania	8	60

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31   Grouping followed five regions used by the UN: https://unstats.un.org/unsd/methodology/m49/

Level at which responding organisations of persons with disabilities work

A majority of OPD respondents reported that they primarily work at the national level (Figure 6). In total, 149 (32.1%) respondents reported that their organization mainly worked at the local level, 253 (54.5%) respondents reported working at the national level, 39 (8.4%) at the regional level, and 23 (5%) at the international or global level.

Figure 5 – Level at which OPD respondents mostly work.

Numbers of respondents:

1 – National: 253   2 – Local: 149

3 – Regional: 39   4 – Global: 23

Groups represented by responding organisations of persons with disabilities

Table 3 and Figure 6 below represents the distribution of constituencies represented by responding organisations of persons with disabilities. A single OPD may have reported representing more than one constituency. Groups most represented by responding OPDs are persons with physical impairments (37.2%), followed by deaf people (30.9%), blind or partially sighted people as much as people with intellectual disabilities (both 29.1%), people with multiple impairments (24.1%) and people with autism (20.1%).

Figure 6 – Groups of persons with disabilities represented by respondent OPDs – Distribution by type of impairment group and intersection with other identity factor.

GROUPS OF PERSONS WITH DISABILITIES	NUMBERS OF DPOS REPRESENTING THESE GROUPS
Indigenous person with disabilities	193
Older people with disabilities	264
Children with disabilities	298
Women with disabilities	336
People with mutltiple impairments	141
People with a chronic disease	71
People with epilepsy	70
People with a cognitive impairment	91
People affected by leprosy	44
People with albinism	60
People with short stature/litte people	71
People with a psychosocial disability	106

Part 1   **Part 2**   Part 3   Part 4   Part 5   Part 6   Conclusions

GROUPS OF PERSONS WITH DISABILITIES	NUMBERS OF DPOS REPRESENTING THESE GROUPS	
Peoplez with autism	115	
People with an intellectual disability	167	
People with deafblindness	100	
Hard of hearing people or people having other…	151	
Deaf people	177	
People with physical impairments	213	
Blind or partially sighted people	167	

Table 3 - Groups of persons with disabilities represented by respondent OPDs – Distribution by type of impairment group and intersection with other identity factor.

PER TYPE OF IMPAIRMENT GROUP:	NUMBER	PERCENTAGE
People affected by leprosy	44	7,7%
People with albinism	60	10,5%
People with epilepsy	70	12,2%
People with short stature/little people	71	12,4%
People with a chronic disease	71	12,4%
People with a cognitive impairment	91	15,9%
People with deafblindness	100	17,5%
People with psychosocial disabilities	106	18,5%
People with autism	115	20,1%
People with multiple impairments	141	24,6%
Hard of hearing people or people having other hearing difficulties	151	26,4%
Blind or partially sighted people	167	29,1%
People with intellectual disabilities	167	29,1%
Deaf people	177	30,9%
People with physical impairments	213	37,2%

PER INTERSECTION WITH OTHER IDENTITY FACTOR:	NUMBER	PERCENTAGE
Women with disabilities	336	58,6%
Children with disabilities	298	52,0%
Older people with disabilities	264	46,1%
Indigenous persons with disabilities	193	33,7%

3 What OPDs generally report about participation of persons with disabilities in decision-making

❯ Key findings:

- **Participation is not equal across different constituencies of persons with disabilities**, and some groups (pers(persons with intellectual disabilities, persons with psychosocial disabilities).
- **There is a trend for the more a disability constituency is represented by OPDs, the more likely it is to be involved** by governments, UN or funding agencies, which aligns with the role established by the CRPD for OPDs as intermediary bodies between policy makers and persons with disabilities, and also highlights the critical responsibility of OPDs to ensure diverse representation and leadership.
- **OPDs are consulted in priority on issues specific to disability**, such as disability laws and policies, and to a lesser extent **but also on wider issues, mostly pertaining to social and economic rights** (education, health, employment, social protection).
- **OPDs are more involved by their governments than by the UN or funding agencies**, and there are also more formal mechanisms for their engagement at government level.
- **Preconditions for participation of persons with disabilities are still insufficient**: gaps in accessibility of the physical environment, accessibility of information and communication, lack of positive attitudes and knowledge of how to engage with persons with disabilities, as well as lack of funding for reasonable accommodation all lead to barriers to participation.
- Yet overall, participation evolves in a positive way: as compared to one year ago, **OPDs perceive that their involvement and influence are increasing with governments or regional organisations, with UN agencies and with funding agencies**.
- As mentioned OPDs are more involved by their governments than by UN or funding agencies but the satisfaction of OPDs with this involvement paints a different picture. With regards to overall satisfaction, **OPDs are less satisfied** (31% pleased, 45.6% displeased) **with their governments than they are with funding agencies** (44.7% pleased, 18.7% displeased), while **perceptions are mixed or unclear with the UN** (30.3% pleased and 21% displeased − and a large 40.2% who are unsure).

Groups of persons with disabilities invited to participate

General Comment 7 of the CRPD Committee stresses the importance of consulting and actively engaging with organisations of persons with disabilities, ensuring representation of a wide diversity[32], in terms of impairment groups, levels (local to global as relevant to the matter of consultation), background including age, sex, language, ethnic, indigenous or social origin, sexual orientation and gender identity, religious and political affiliation, and migrant status or other status.

Table 4 below compares consultation of different constituencies of persons with disabilities respectively by governments, the UN and funding agencies[33]. From this data, groups that are most frequently mentioned as involved by governments, UN and funding agencies are persons who are blind or partially sighted, persons with physical impairments, deaf persons and women with disabilities. Persons of short stature, persons affected by leprosy, persons with a cognitive impairment, persons with epilepsy or persons with a chronic disease are perceived as less involved, some of which may be related to prevalence in some contexts, which the survey does not allow to capture. In further comments shared through open-ended questions however, persons with intellectual disabilities and persons with psychosocial disabilities are the groups most often explicitly mentioned as not involved.

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.

People with the most common disabilities, this participation happens more frequently. However, for people with less common disabilities, things are very different indeed. The phrase «For Everyone» does not effectively exist.
— Survey respondent from Brazil.

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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32 CRPD/C/GC/7, in particular para. 15, 27, 40, 76, 90, 94.g

33 This only captures responses from OPD respondents who indicated above that their organisation is involved (in formal or informal ways) with these stakeholders – filtered as having direct experience of engagement.

Table 4 – Involvement of different constituencies of persons with disabilities by government, UN and funding agencies as perceived by OPD respondents engaged with these stakeholders.

PER TYPE OF IMPAIRMENT GROUP.	GOVERNMENT	UN	FUNDING AGENCIES
Blind or partially sighted people	40,6%	42,6%	52,1%
People with physical impairments	43,6%	43,4%	54,3%
Deaf people	37,1%	40,2%	47,1%
Hard of hearing people or people having other hearing difficulties	25,6%	31,1%	42,1%
People with deafblindness	19,9%	18,0%	23,6%
People with an intellectual disability	24,8%	26,2%	27,9%
People with autism	19,3%	17,2%	25,0%
People with a psychosocial disability	20,7%	21,3%	24,3%
People with short stature/little people	12,3%	7,4%	16,4%
People with albinism	10,4%	9,8%	15,0%
People affected by leprosy	7,6%	6,6%	15,0%
People with a cognitive impairment	12,8%	9,0%	15,0%
People with epilepsy	10,9%	9,0%	15,0%
People with a chronic disease	12,8%	6,6%	14,3%
People with multiple impairments	16,1%	13,9%	22,9%

PER INTERSECTION WITH OTHER IDENTITY FACTOR	GOVERNMENT	UN	FUNDING AGENCIES
Women with disabilities:	27,8%	33,6%	40,0%
Children with disabilities:	19,1%	20,5%	27,9%
Older persons with disabilities:	17,2%	12,3%	17,9%
Indigenous persons with disabilities	13,1%	19,7%	17,9%

Figure 7 - Involvement of persons with disabilities by governments, UN & funding agencies vs representation by OPDs - by constituency.

Legend: ■ Consulted (all stakeholders) — — Represented by OPDs
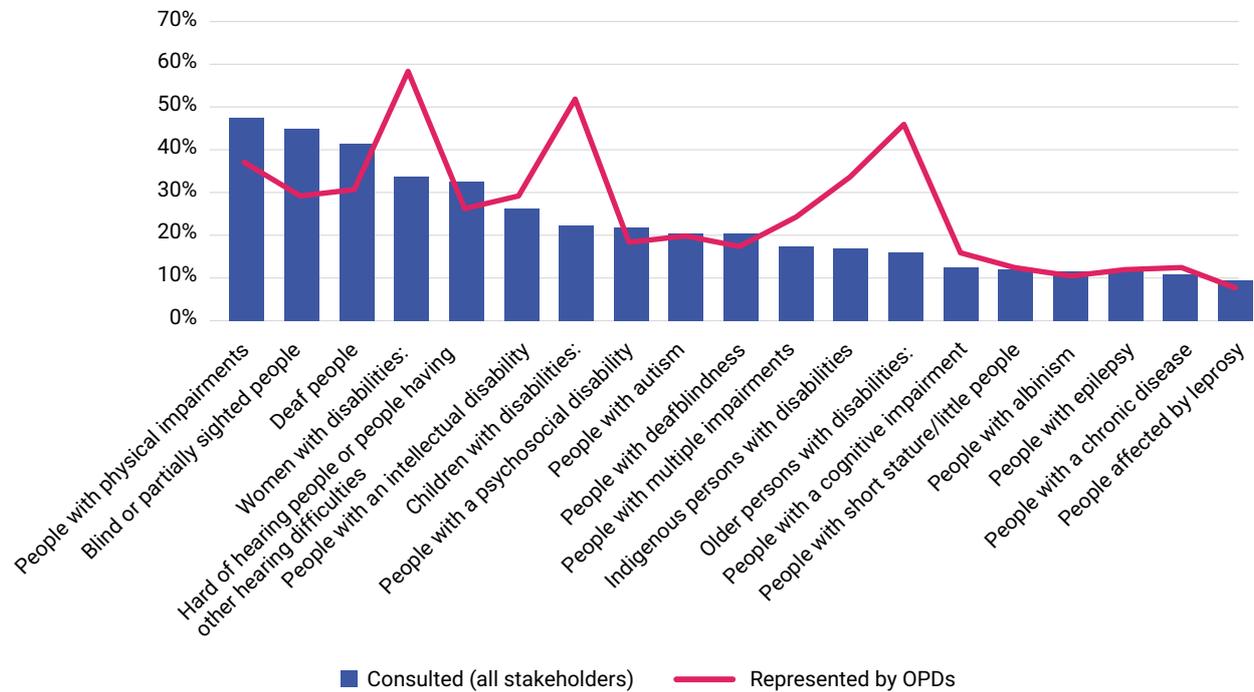
Comparison between representation of different constituencies of persons with disabilities by OPDs and involvement of the same constituencies by government, the UN or funding agencies suggests that the more groups are represented in OPDs, **the more likely they are to be involved by decision-makers**. It may indicate that OPDs are more likely to be consulted and to put forward disabilities related issues rather than gender age or ethnicity related issues as the greatest gaps which are also outliers between representation and consultation are with women, children, indigenous and older persons with disabilities. Among the groups that are the most consulted, people with physical disabilities, blind and partially sighted people, deaf people and hard of hearing people are slightly more involved

than their representation in OPDs, which may be explained by the fact that they often occupy a position of leadership in OPDs and may be the primary interlocutors of governments, the UN or funding agencies. It may also be related to the fact that historically those are the groups for which disability related interventions (accessibility, assistive devices, rehabilitation, education …) were implemented. This also suggests that **representation of the diversity of persons with disabilities by OPDs is essential to ensure involvement of the diversity in decision-making, and highlights the critical responsibility of OPDs, as proxy for representation, to ensure diverse representation in their leadership**.

Issues on which OPDs are consulted

Article 4.3 defines the scope of participation as "concerning issues relating to persons with disabilities". This should be interpreted broadly and covers the full range of legislative, administrative and other measures that may directly or indirectly impact the rights of persons with disabilities. As recalled by the General Comment 7, examples of issues directly affecting persons with disabilities are deinstitutionalization, social insurance and disability pensions, personal assistance, accessibility requirements and reasonable accommodation policies. Measures indirectly affecting persons with disabilities might concern constitutional law, electoral rights, access to justice, and the appointment of the administrative authorities governing disability-specific policies or public policies in the field of education, health, work and employment[34]. This is meant to ensure consideration for the rights of persons with disabilities on an equal basis with others in all areas of life.

The reality captured by the IDA Global Survey shows that the highest share of responses on participation across all types of stakeholders (governments, UN and funding agencies) concerns disability-specific issues. However, cumulated responses on other 'mainstream' issues suggest that **OPDs are also consulted in a wide range of areas not specific to disabilit**y (see details in Table 5 below):

- Highest response rates go to (ordered by decreasing priority) to social and economic issues in the areas of education, health, employment, social protection, for which OPDs appear to engage proportionally more with governments.

- These are followed by gender equality, access to justice, participation in political life, protection against violence, poverty and disaster risk reduction and humanitarian action.
- Issues selected but with much smaller occurrence of responses include: water and sanitation, urbanisation and housing, nutrition, environment and climate change.

Topics of consultation are similar across government, UN and funding agencies, with health, education, social protection and employment being topics where consultations by government is relatively higher, while funding agencies consult OPDs slightly more on DRR & humanitarian action and gender equality.

However it is to be noted that there is a drop of 30% between consultation by UN and Funding agencies on disability specific issues and education, the second most mentioned subject, against only 10% drop for government with higher involvement also on employment, health and social protection.

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34   CRPD/C/GC/7 para 20.

Table 5 – Issues on which OPDs are involved by governments, UN and funding agencies (% as indicated by respondents who indicated being involved with these stakeholders).

ISSUES	GOVERNMENT	UN	FUNDING AGENCIES
Disability specific issues, for example working on laws on disability	69,5%	75,4%	72,9%
Education	59,7%	36,9%	41,4%
Employment	48,8%	30,3%	32,1%
Health	46,3%	33,6%	36,4%
Social protection	46,3%	32,8%	25,7%
Access to justice	38,4%	27,0%	22,9%
Gender equality	31,9%	36,9%	27,1%
Participation in political life	31,9%	21,3%	23,6%
Poverty reduction	29,4%	26,2%	23,6%
Protection against violence	28,3%	25,4%	19,3%
Disaster risk reduction and humanitarian action	18,5%	23,0%	15,0%
Urbanisation/housing	13,4%	11,5%	7,1%
Nutrition	10,6%	12,3%	10,0%
Water and sanitation	10,1%	9,0%	7,1%
Environment and climate change	7,6%	8,2%	7,9%
Other	12,3%	5,7%	11,4%
Don't know	3,8%	3,3%	5,7%

Considering that disability is a cross-cutting issue, and that it is essential that concerns of persons with disabilities are mainstreamed across all areas of society, it is worth noting that the share of OPDs that report being involved only on disability-specific issues is of 18% with government, 10% with the UN and 11% with funding agencies.

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).

Looking at it from the lens of SDGs and CRPD, OPDs are usually more informed and involved by governments in realising and monitoring the CRPD than in the SDGs, as reflected in Figure 8 and Table 6 below.

Figure 8 – Ways in which OPDs are informed/ involved with the SDGs vs the CRPD.

■ Working to achieve the SDGs   ■ Realise and monitor the CRPD
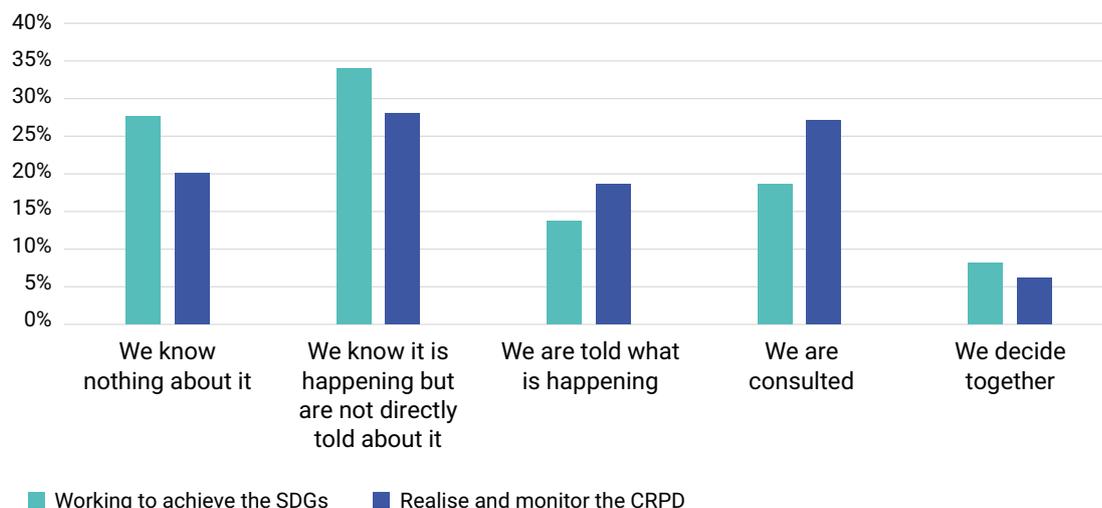
Table 6 – Ways in which OPDs are informed/ involved with the SDGs vs the CRPD.

WAYS IN WHICH PEOPLE ARE INFORMED	■ WORKING TO ACHIEVE THE SDGS	■ REALISE AND MONITOR THE CRPD
We know nothing about it	27%	20%
We know it is happening but are not directly told about it	34%	28%
We are told what is happening	13%	18%
We are consulted	18%	27%
We decide together	8%	6%

Involvement of OPDs with decision-makers in formal or informal ways

"Close consultation" and "active involvement" are relatively undefined notions, but convey a sense of quality, extent of participation, ensuring regular, open, timely and meaningful roles of OPDs[35]. The IDA Global Survey seeks to unpack this by looking at different characteristics.

The existence formal mechanisms for consultation is considered here as an indicator of the willingness of a decision-maker to effectively extend participation to civil society groups. While it does not guarantee the openness of decision-makers to effectively engage in dialogue and allow for influential and transformative participation, existence of such mechanisms is at least a sign of willingness to consider (or at worst to display) OPD participation as a sign of commitment to establish a regular form of interaction.

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35   CRPD/C/GC/7 para 22

In order to fulfil their obligations under Article 4.3, States are also required to "adopt legal and regulatory frameworks and procedures (…)", to "adopt provisions granting OPDs seats on, for example, standing committees and/or temporary task forces"[36], and to "establish and regulate formal consultation procedures, including the planning of surveys, meetings and other methods, setting up proper time frames, early engagement of organizations of persons with disabilities, and prior, timely and broad dissemination of relevant information for each process"[37].

Overall, **respondents indicated higher levels of involvement with government than with UN agencies or programmes and funding agencies**. This can be explained by the fact that States are the primary duty bearers with regards to realisation of the CRPD and identified as key interlocutors by OPDs, and a lesser degree of familiarity with the UN and funding agencies (illustrated by higher response rates on 'I don't have enough information to answer this question').

OPD engagement is more formal with the government (43.1%), funding agencies (35.4%) and less with the UN (19%). While formal mechanisms may facilitate engagement on a regular basis, they are not sufficient to ensure meaningful participation. The next section explores more in depth preconditions for OPD engagement in decision-making.

Figures 9 – Involvement of OPDs with governments, UN and funding agencies (valid %).
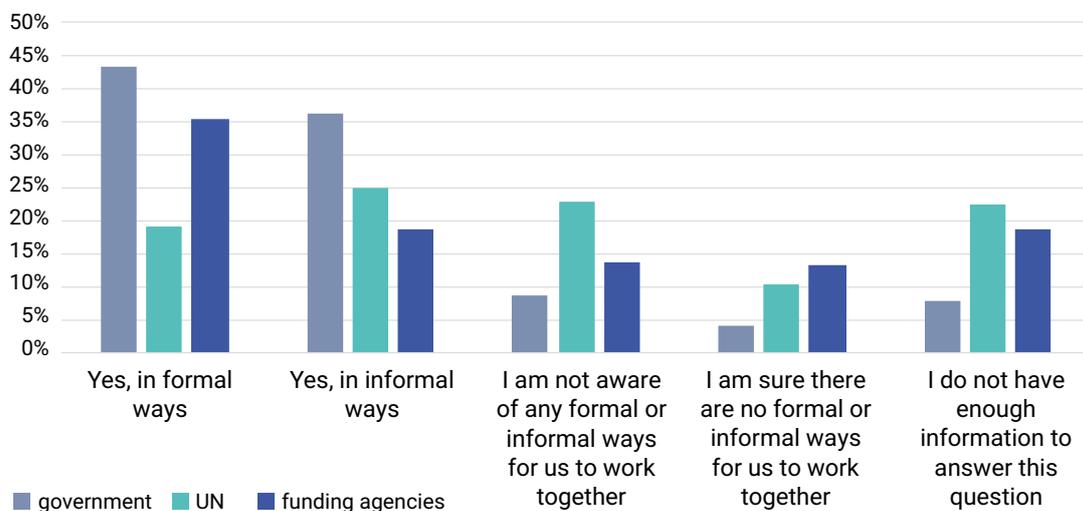
36 CRPD/C/GC/7 Para 53

37 CRPD/C/GC/7 Para 54

Table 7 – Involvement with governments, UN and funding agencies: for each of government, UN and funding agency involvement, the total number of respondents endorsing each response option is given (and the percentage this constitutes of the overall responses for each column).

INVOLVEMENT OF OPD RESPONDENTS	GOVERNMENT	UN	FUNDING AGENCIES
yes in formal ways	43,1%	19,0%	35,4%
yes in informal ways	36,1%	25,1%	18,8%
I am not aware of any formal or informal ways for us to work together	8,7%	22,9%	13,8%
I am sure there are no formal or informal ways for us to work together	4,1%	10,4%	13,1%
I don't have enough information to answer this question	8,0%	22,6%	18,8%

Ensuring preconditions for participation of persons with disabilities

General Comment 7 extensively refers to the obligation for States to "ensure accessibility for persons with disabilities to all facilities and procedures related to public decision-making and consultation". It recalls the scope of measures and areas that are concerned[38], and the importance of ensuring these in a timely manner and without additional costs.

Findings from the IDA Global Survey show that **preconditions for participation of persons with disabilities are still insufficient which leads to barriers to participation**. Most respondents indicated that accessibility of the physical environment, accessibility of information and communication, positive attitudes, knowledge of how to ensure participation and funding for reasonable accommodations are only ensured in some ways. Discrepancies can be observed between stakeholders, with UN and funding agencies performing better than the government[39]. The fact that OPDs are less familiar with the UN is visible in higher number of respondents indicating they are not sure if those preconditions are met (see more in the next sections, per type of stakeholders).

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38 CRPD/C/GC/7 para 45

39 This be explained by the fact that some respondents expanded their comments on the inclusiveness and accessibility of all governments services and not on inclusiveness of consultation mechanisms.

Figure 10 – Preconditions for meaningful participation of persons with disabilities in the work of the government.
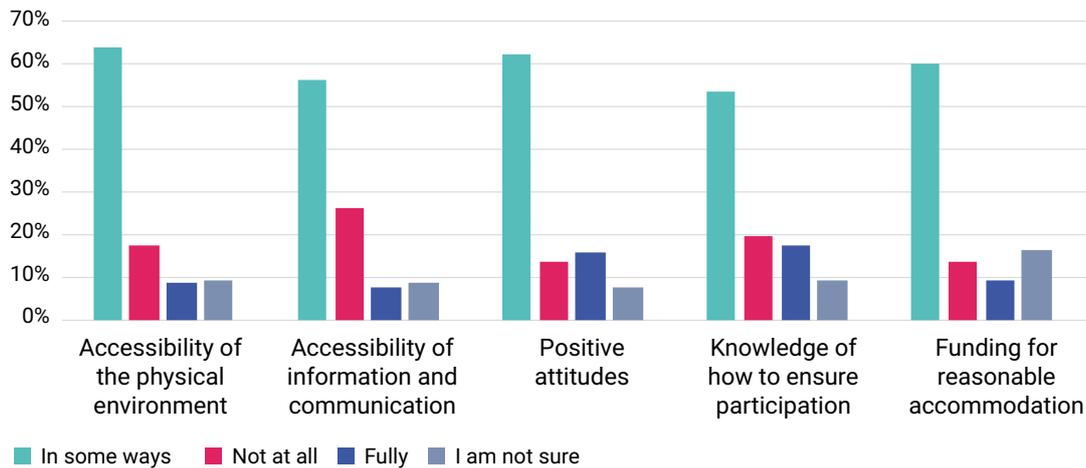
Table 8 – Preconditions for meaningful participation of persons with disabilities in the work of the government.

GOVERNMENT	ACCESSIBILITY OF THE PHYSICAL ENVIRONMENT	ACCESSIBILITY OF INFORMATION AND COMMUNICATION	POSITIVE ATTITUDES	KNOWLEDGE OF HOW TO ENSURE PARTICIPATION	FUNDING FOR REASONABLE ACCOMMODATION
In some ways	64%	57%	62%	54%	60%
Not at all	18%	26%	14%	20%	14%
Fully	9%	8%	16%	17%	9%
I am not sure	9%	9%	8%	9%	17%

Figure 11 – Preconditions for meaningful participation of persons with disabilities in the work of the UN entity considered the most inclusive.
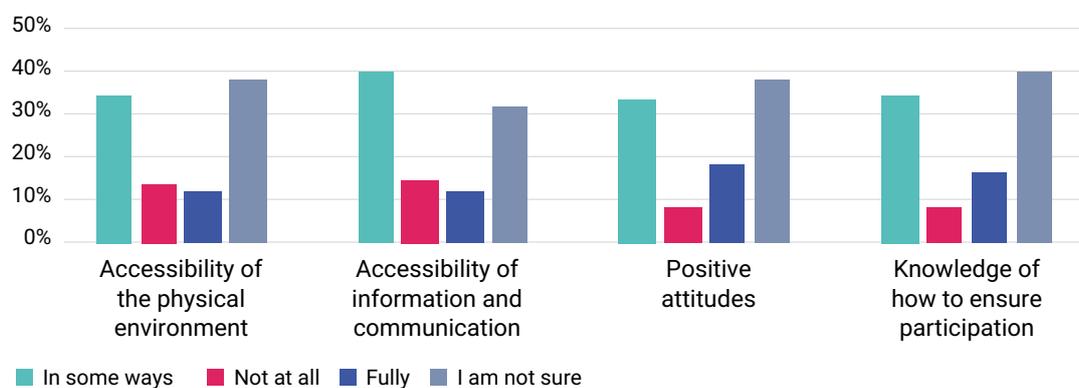
Table 9 – Preconditions for meaningful participation of persons with disabilities in the work of the UN entity considered the most inclusive and in the work of the UNPRPD.

UN AGENCY SELECTED AS MOST INCLUSIVE	ACCESSIBILITY OF THE PHYSICAL ENVIRONMENT	ACCESSIBILITY OF INFORMATION AND COMMUNICATION	POSITIVE ATTITUDES	KNOWLEDGE OF HOW TO ENSURE PARTICIPATION
In some ways	35%	41%	34%	35%
Not at all	14%	15%	8%	9%
Fully	12%	12%	18%	16%
I am not sure	39%	32%	39%	40%

Figure 12– Preconditions for meaningful participation of persons with disabilities in the work of the funding agency considered the most inclusive.

Legend: In some ways | Not at all | Fully | I am not sure
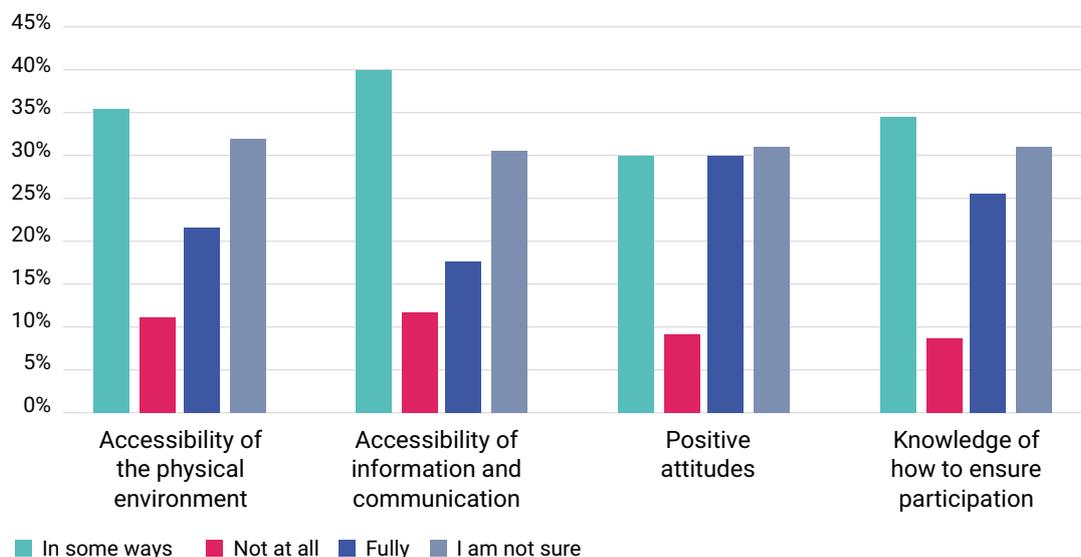
Table 10 – Preconditions for meaningful participation of persons with disabilities in the work of the funding agency considered the most inclusive.

MOST INCLUSIVE FUNDING AGENCIES	ACCESSIBILITY OF THE PHYSICAL ENVIRONMENT	ACCESSIBILITY OF INFORMATION AND COMMUNICATION	POSITIVE ATTITUDES	KNOWLEDGE OF HOW TO ENSURE PARTICIPATION
In some ways	35%	40%	30%	35%
Not at all	11%	12%	9%	9%
Fully	22%	18%	30%	25%
I am not sure	32%	31%	31%	31%

Quantitative responses as well as comments suggest that, while intentions may be there…:
Legal provisions are not enacted and measures are not taken to effectively ensure participation:
Though a comprehensive regulation is in place, efforts by the State to implement the regulation is very minimal or not at all. The Government does not have the champions within and the required political leadership is not visible by the governments which have been in office in the last 10 years...
— Survey respondent from Sri Lanka.

Because the barrier is the mentality, and it is thought that persons with disabilities are not to be consulted, the poor interpretation of the law means that anyone does what they want.

— Survey respondent from Cameroon.
Many initiatives and changes have been recorded, but they are not implemented in practice or interpreted by government institutions and services in their own way. They always oppose the lack of financial resources to ensure accessibility.
— Survey respondent from Slovenia.

Despite the ratification of the CRPD, expression of commitment to the 2030 development agenda, and enacting several disability legislations, practical implementation is still a challenge. No adjustments have been made to fully include Persons with Disabilities. For example, a deaf lady was recruited as agenda officer in the Ministry of Gender, Labour and Social Development. However, since, her recruitment she has had to work without sign language interpreter which affects her effectiveness and interactions on her job.
— Survey respondent from Uganda.

Efforts to ensure participation remain ad-hoc, and do not allow for realistic timelines:
If requested the Government makes meetings and consultations accessible. This is not always done automatically but once requested it is usually provided. There have been occasions where even once requested accessibility was forgotten.
— Survey respondent from Canada.

In most cases, meetings are often held in places where government agencies would have planned and most cases would often be inaccessible. It is when our DPO, if informed well in advance would request for change of venue to accessible venue otherwise we often would not attend due to inaccessibility.
— Respondent from Papua New Guinea.

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.

Some of the buildings and other infrastructures are still not yet accessible due to lack of ramps, guides and other accessibility assistance.
— Survey respondent from the Philippines.

The government wanting to progress things quickly is sometimes a barrier or excuse for not providing full accessibility measures.
— Survey respondent from New Zealand.

Partial or poor quality of adaptations such as reasonable accommodation actually nullifies the opportunity to participate:
Too often accessibility don't meet standard, take for example sign language interpreters are not certified and the Sign language inset on TV are so tiny , government are not ready to cover cost for accessibility, too often there is no interpreters during meetings.
— Survey respondent from Kenya.

*We can recall a meeting organized by *** on the Disability Bill and CRPD. They even didn't bother to provide captioning and Sign Language interpreting; when objected in meeting they invited a man to do interpreting who didn't know more than a few signs.*
— Survey respondent from Pakistan.

In government's actions or activities, we usually have some accessible information for blind (soft copies), partially sighted people (soft copies, accessible websites) and deaf people (sign language, closed captions in recorded videos). Usually instant captioning and Braille are not available, and reasonable accommodations are very hard to get. Easy-to-read and PAs are NEVER EVER available. If you manage to have your own PA, he or she will be able to be with you all the time, but probably will be treated as your caregiver and sometimes it gets really uncomfortable, in this situation the attitudinal barrier is very strong.
— Survey respondent from Brasil.

We worked to develop a national plan, propose legislation and several trainings. The contents were highly technical, with long and exhausting sessions. This made effective participation of people with intellectual and psychosocial disabilities difficult.
— Survey respondent from Paraguay.

Evolution of OPD involvement and influence as compared with one year ago

The IDA Global Survey aimed to capture OPDs' perception of trends in participation over time. Respondents were asked to compare their current level of involvement and level influence with government or regional organisations, the UN, and funding agencies with their level of involvement and influence a year ago[40].

Overall, as compared to one year ago, organisations of persons with disabilities perceive that their involvement and influence are increasing with governments or regional organisations, with UN agencies and with funding agencies.

There are also positive comments testifying to the fact that things are changing:
We see this new trend of providing money for transportation, personal assistant, or interpreter, which is excellent. How about working together so that disabled people can be empowered and have their own transportation, etc.
— Survey respondent from an OPD active in several African countries (about the UN).

There are similarities in evolutions of OPD involvement and of OPD influence as compared with one year ago across the three types of stakeholders (as confirmed by chi-square test for independence). There are no significant differences between the perceived levels of involvement and the perceived levels of influence, which suggest that OPDs perceive that when they are involved, they do have influence. OPDs gave examples of impact directly attributed to their engagement: these are in majority examples of OPD influence on policy review/ reform, accessibility, social protection, awareness of the rights of persons with disabilities and access to elections.

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40   To increase the expected cell frequencies for chi-square analyses, the response categories of "it improved a lot" and "it improved in some ways" were combined; and the response categories of "it got a lot worse" and "it got worse in some ways" were combined. Three response categories were therefore used for chi-square analyses: "it improved", "it stayed the same", and "it got worse".

Figure 13 – Evolution of OPD involvement and influence with government, UN and funding agencies, as compared to one year ago.

Figure 13 – Evolution of OPD involvement and influence with government, UN and funding agencies, as compared to one year ago.
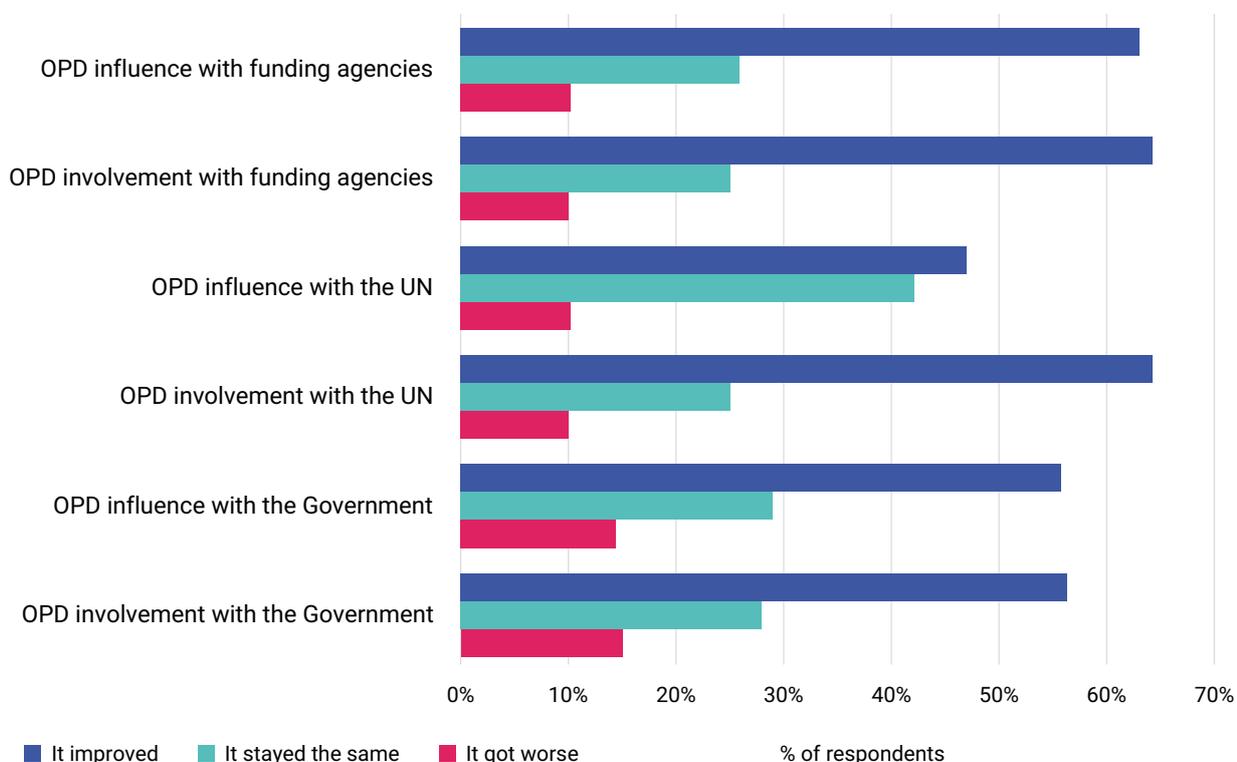
Table 11– Evolution of OPD involvement and influence with government, UN and funding agencies, as compared to one year ago.
(% of respondents to the questions: Compared with one year ago, how do you feel the involvement/ influence of your DPO with your government / the UN / funding agencies has changed?)

	WITH GOVERNMENT		WITH THE UN		WITH FUNDING AGENCIES	
	Involvement	Influence	Involvement	Influence	Involvement	Influence
It improved	56,70%	56,20%	64,70%	47,30%	64,70%	63,60%
It stayed the same	28,20%	29,20%	25,30%	42,40%	25,30%	26,10%
It got worse	15,10%	14,60%	10%	10,30%	10%	10,30%

Positive trends in engagement of OPDs are also reflected in a trend of increasing funding as compared to one year ago (see more in Part 6).

Overall satisfaction of OPDs with their engagement

The many limitations to participation analysed above are reflected in OPDs' overall appreciation of their engagement. Responses to questions on satisfaction show that OPDs are more displeased (45.6%) than pleased (31.0%) with their engagement with the government. They are overall more pleased (44.7%) than displeased (18.7%) with their engagement with funding agencies, however with a large percentage of respondents who are unsure (29.4%). With the UN, this percentage of unsure rises to 40.2% with less contrast between those who are pleased (30.3%) and displeased (21.0%).

Figure 14– Satisfaction of OPD respondents with their engagement with government, UN and funding agencies (% of respondents).

■ With funding agencies ■ With governments or regional organisations ■ With the UN
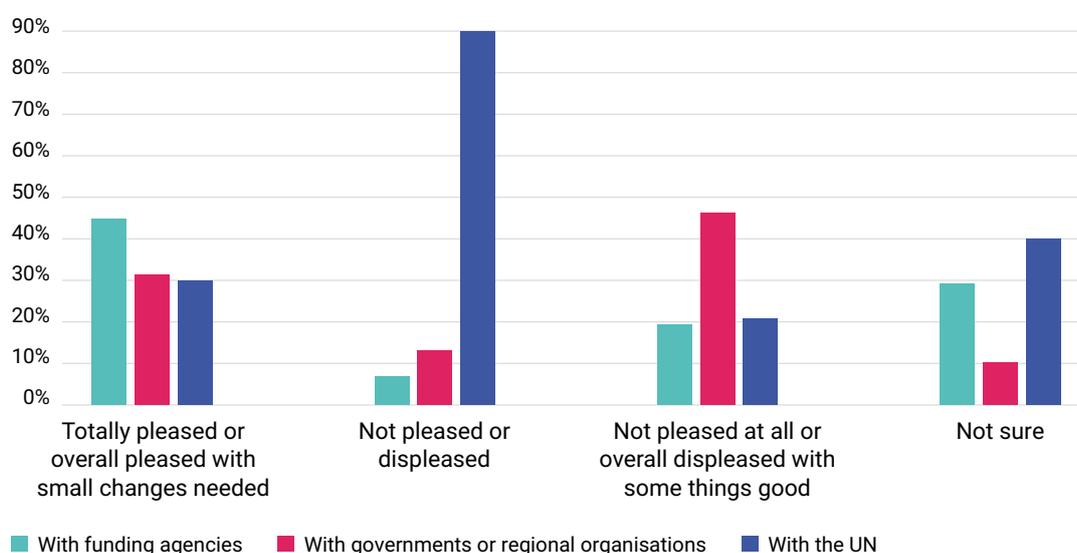
Table 12 – Satisfaction of OPD respondents with their engagement with government, UN and funding agencies.

OVERALL, AS A DPO, HOW PLEASED ARE YOU WITH THE WORK YOU HAVE DONE WITH YOUR GOVERNMENT / WITH THE UN / WITH FUNDING AGENCIES:	WITH FUNDING AGENCIES (%)	WITH GOVERNMENT (%)	WITH THE UN (%)
Totally pleased or overall pleased with small changes needed	44,70%	31,00%	30,30%
Not pleased or displeased	7,30%	13,00%	8,50%
Not pleased at all or overall displeased with some things good	18,70%	45,60%	21,00%
Not sure	29,40%	10,40%	40,20%

This is also reflected in the way OPDs qualify their experience of engaging with these stakeholders:

Figure 15 – How OPDs characterize their experience of engagement with decision-makers

■ Very poor or poor ■ Mixed ■ Good or very good
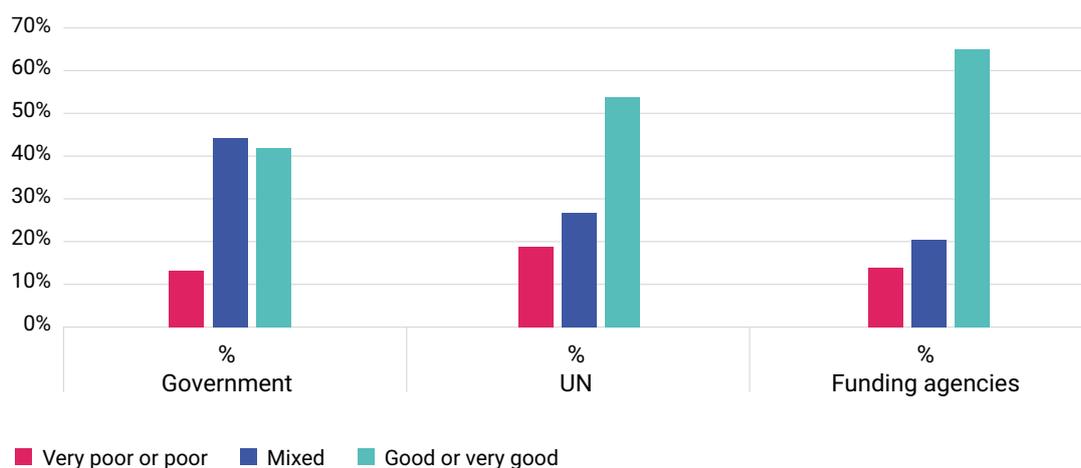
Table 13 – How OPDs characterize their experience of engagement with decision-makers.

EXPERIENCE OF ENGAGEMENT WITH DECISION-MAKERS	GOVERNMENT	UN	FUNDING AGENCIES
■ Very poor or poor	13%	19%	14%
■ Mixed	44%	27%	20%
■ Good or very good	42%	54%	66%

4

Participation of organisations of persons with disabilities with governments

> ## Key findings:

- **Involvement of OPDs with governments is still insufficient, as compared to the standards set by the CRPD**, with a majority of OPDs reporting they are sometimes invited - regardless of the fact that the involvement with governments are at higher level than with UN and funding agencies.

- Across stages of the government policy and/or programme cycle, OPDs usually do not participate in budget decisions: **47% of OPDs report that they are never consulted or and 19% rarely consulted, in budget decisions by their government**.

- **Levels of information and opportunity to influence are low**, with very few respondents indicating high roles of co-decision, and the majority reporting that they know things are happening but are not directly informed about it.

- Although some OPDs do get support from their government to participate, **numerous comments highlight the lack of resources and financial support to exist and operate**.

- A clear majority of OPDs (54,4%) perceive that **other civils society groups have more opportunities to participate than OPDs**.

- Overall, 42% of OPDs consider that their experience of engagement with their government is poor or very poor, 44% have a mixed experience **and only 13% consider it good or very good**.

- **Recommendations from OPDs to governments** focus on the provision of financial support to OPDs, a demand for inclusion of all groups of persons with disabilities, a call for enhanced consideration for their views and meaningful roles in shared decision-making, ensuring accessibility and reasonable accommodation, or access to capacity development. They also recommend that governments should hire more persons with disabilities and train their personnel on the CRPD as well as how to engage with persons with disabilities.

Participation of OPDs across stages of government policy or programme cycle

To be meaningful, participation should not be reduced to specific stages of the programme or policy cycle. The right to participate needs "**to be applied to decision-making, implementation and monitoring processes** related to the Convention. By guaranteeing the participation of organizations of persons with disabilities **at each of these stages**, persons with disabilities would be able to better identify and point out measures that could either advance or hinder their rights, which ultimately yields better outcomes for such decision-making processes. Full and effective participation should be understood as a process, not as an individual one-time event"[41]. Results of the IDA Global Survey show that **compared to the standards set by the CRPD, involvement with governments is still insufficient**, as illustrated by the high number of OPDs responding they are only sometimes invited. While government's democratic cultures and practices may vary, and habits of participatory budgeting or civil society consultation in budget making may not be very widespread, results show overall lean levels of participation. Overall, across all steps of the government policy or programme cycle, a very small number of OPDs report being always invited. This data also confirms the empirical observations made by IDA and IDA members that OPDs are not invited to stages that one can assume to be more influential, i.e. budgeting and monitoring of results.

Figure 16 – Frequency of OPD participation, by level of OPD work.
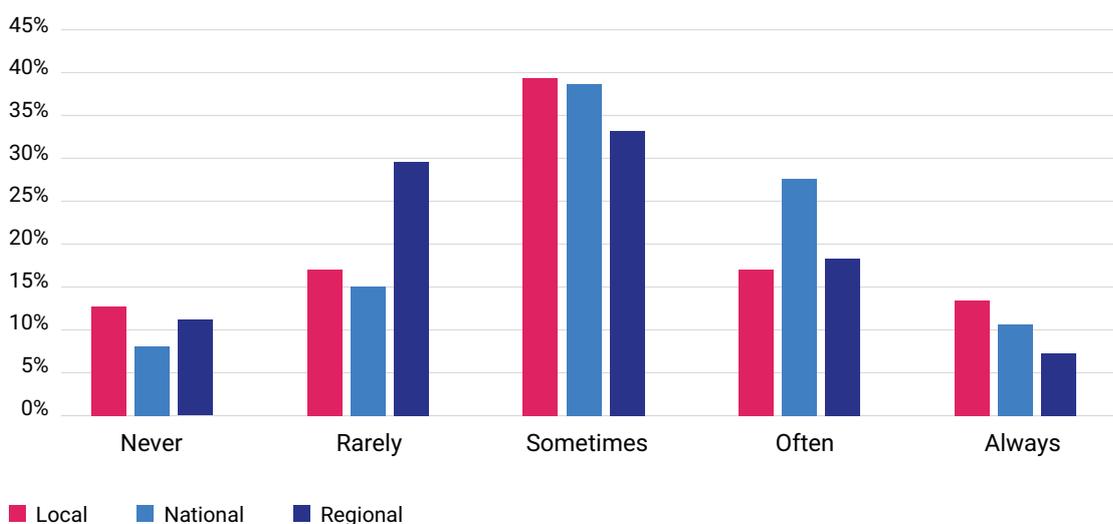
FREQUENCY OF OPD PARTICIPATION	LOCAL	NATIONAL	REGIONAL
Never	13%	8%	11%
Rarely	17%	15%	30%
Sometimes	40%	39%	33%
Often	17%	28%	19%
Always	13%	11%	7%

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41   CRPD/C/GC/7 para 28

Planning

Lack of participation in planning policies and programmes results in deprioritizing issues that are important to persons with disabilities, or worse, in adopting measures that perpetuate exclusion and discrimination. Results show that practices across levels of government are very diverse, with 37% OPDs that are sometimes involved in planning, 31% that are never or rarely involved, and 30% that are often or always involved. Results show some differences between levels of government, with more diverse levels of involvement at the local level, slightly higher participation at the national level, and lower at the regional level.

Budget decisions

Results show clearly that OPDs are not associated to budget decisions. **66% of OPDs report that they are never (47%) or rarely (19%) consulted in budget decisions by their government** (across levels). With the UN entity or programme that they consider the most inclusive, only 3% of OPDs say they are involved at the planning stage.

Policy / programme implementation, data collection

Findings around involvement in implementation of programmes and policies and in data collection show diverse responses, with lower participation than in the policy or programme planning stage. **46% of OPDs report that they never or rarely are involved in implementation, and 47% that they never or rarely are involved in data collection**.

Monitoring

Monitoring the outcomes of policy and programmes is one of the key roles that civil society can play to hold decision-makers accountable. Yet overall, **50% OPDs report that they are never or rarely involved in monitoring**.

Detailed findings per stage of the programme or policy cycle are provided in Annex 4. The survey also sought to capture levels of shared decision-making, from absence of information to co-decision. Across stages, results show that OPDs are aware that processes are taking place but are not directly informed. They tend to know more about activities related to planning and implementation than to budgeting, data collection or monitoring. **On average, less than 1 OPD out of 4 reports to be consulted by their governments, and only 1 out of 15 reports to have a more meaningful role through co-deciding.**

Figure 17 – Level of shared decision-making of OPDs with government, by stage of the policy/ programme cycle.
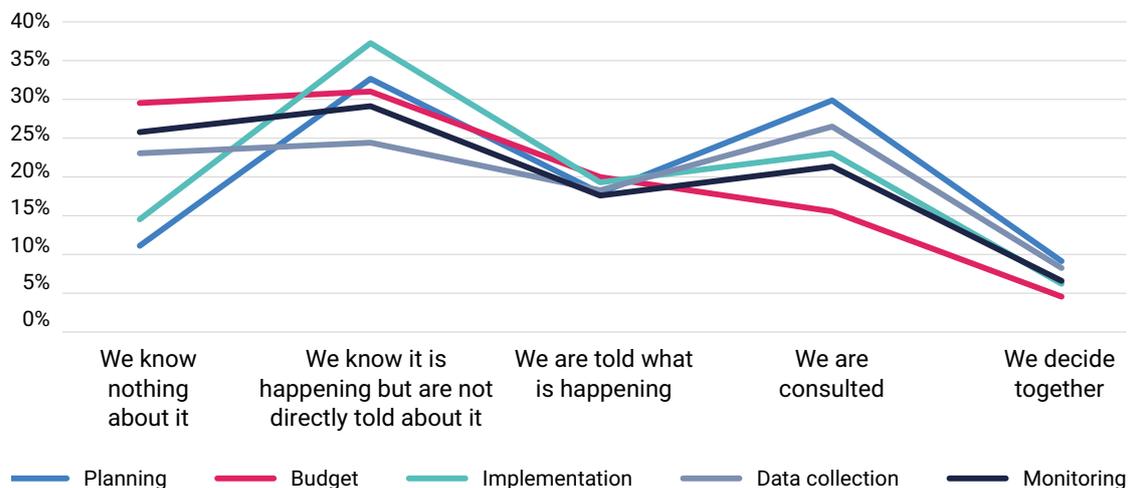
Table 14 – Level of shared decision-making of OPDs, by stage of the policy/ programme cycle.

	PLANNING	BUDGET	IMPLEMENTATION	DATA COLLECTION	MONITORING
We know nothing about it	11%	30%	14%	23%	26%
We know it is happening but are not directly told about it	33%	31%	38%	24%	29%
We are told what is happening	18%	20%	19%	18%	17%
We are consulted	30%	15%	23%	27%	21%
We decide together	9%	4%	6%	8%	6%
Total	100%	100%	100%	100%	100%

Support provided by government to OPDs

Enabling participation of civil society in public affairs is a core responsibility of governments, also recalled in Article 29 of the CRPD. This includes allocation of financial resources to cover the costs of participation, such as the costs of reaching consultation venues, and other expenses needed to engage in consultation processes on an equal basis with others[42]. **OPD respondents who receive support from government to participate said they mostly receive it in the form of funding (45%), capacity building to understand how to engage (33%) or reasonable accommodation (23%).**

Numerous additional comments in open-ended questions stress that OPDs are confronted with severe lack of resources and are not satisfied with levels of support by their governments. Beyond support to participation in consultation processes and decision-making, OPDs largely commented on the lack of resources to exist and operate, as illustrated by the quotes below. The provision of financial support to OPDs also comes up as the top recommendation to governments (see below).

Only certain advisory committees are remunerated by an attendance fee of 20 Euros per session. Personal assistance is not provided. People with disabilities have to juggle their professional / private life (institutional / care / professional life) and the technical and physical skills to participate in government meetings / work.
— Survey respondent from Luxemburg.

In several Colombian municipalities, the support staff they need, such as interpreters and interpreter-guides, are still not provided by the government, either due to lack of awareness or due to government agencies' lack of funding.
— Survey respondent from Colombia.

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42   CRPD/C/GC/7 para 46

(We get) support for granting various operating authorizations or organizing commemorative events.
— Survey respondent from DR Congo.

We receive $100 U.S. a month from our Government. The support stops there.
— Ssurvey respondent from Belize.

We take part in government work to improve the situations with girls and women with disabilities. We still not received any government support to our organization.
— Survey respondent from Bangladesh.

There is no scheme for funding the watchdog organizations in Georgia.
— Survey respondent from Georgia.

Table 15 – OPD involvement compared to other civil society organizations.

OPD INVOLVEMENT COMPARED TO OTHER CIVIL SOCIETY ORGANIZATIONS	
Disabled Persons Organisations (DPOs) have more opportunities to take part than other civil society groups	12%
Disabled Persons Organisations (DPOs) take part equally with other civil society groups	21%
Other civil society groups have more opportunities than Disabled Persons Organisations (DPOs)	54%
I am not sure	13%

Participation of OPDs as compared to other civil society groups

Respondents were questioned about their opinion on how easy the government makes it for civil society groups to take part with its work. A vast majority (63%) responded in some ways, 14% not at all and 10% that it is not at all easy.

When asked to compare their participation with their perceived participation of other civil society groups, **a clear majority of respondents (54,4%) indicate that other groups have more opportunities to participate than OPDs**. This is true across all kinds of stakeholders (governments, UN, funding agencies) and contexts (least developed to high income countries).

OPDs' experiences of working with their government

As established by the Global Survey, OPDs are more displeased than pleased with their engagement with the government. OPDs most often work with several ministries and are in fact improving inter-sector relation and communication around specific multi-faceted issues, raising awareness that disability is a cross-sectional task. Many OPDs prioritize work with Ministries and Departments focused on Social Justice and Issues, Education, Employment, Welfare, Empowerment, and Gender Issues. Some countries have ministries, cabinets, or departments especially dedicated to persons with disabilities.

Examples provided in response to a question on an impact for which **OPDs' work with their government was essential are largely examples of OPD influence on disability legislation or policy change, improvement in accessibility (especially of transportation, elections or public information), access to social protection/**

social schemes, raised awareness on the rights of persons with disabilities and enhanced opportunities for participation.

A major change was introduced to public service employment after persons with disabilities were excluded from public service, because of some obsolete laws; this changed, and a quota for employment in the public service was reserved for some candidates from amongst persons with disabilities.
— Survey respondent from Nigeria.

Among those who qualify their experience of working with governments as good or very good, **examples are mostly of two types. OPDs provide great examples of involvement and influence on disability-focused policy or legislation**. Other examples are specific and punctual successes (such as building a ramp, obtaining a licence to run an inclusive school, being invited at a conference) or collaboration being initiated where it did not exist before.
They are willing to partner with us to organise an AT Expo next year in Namibia.
— Survey respondent from Namibia (experience considered very good).

They accepted to start involving DPOs in planning activities in the area as well as when building new school structures.
— Survey respondent from Malawi (experience considered good).

Of the 44% OPDs who gave examples of mixed experience with governments, many have flagged that **the views shared by OPDs are not properly considered**. Some clearly comment on the fact that participation of OPDs is being utilized in a form of co-optation.

We would describe the consultation process as formalistic and (our OPD)'s participation as something that was needed to legitimize the procedure.
— Survey respondent from an OPD active in Europe (experience considered mixed).

Understanding and willingness is very inconsistent. A lot of consultation is rubber-stamping and not meaningful.
— Survey respondent from an OPD active in Africa (experience considered mixed).

We have fear that they just want to show that we were involved but might not include our input.
— Survey respondent from Sierra Leone (experience considered mixed).

Other issues are: the fact that disability is not considered a cross-cutting issue, engagement is irregular, the decision-making space is not shared equitably and views of OPDs are not taken on board, some groups are excluded, decisions are not followed up, not getting enough time to contribute.

Finally, 13% of OPDs who provided examples considered poor or very poor express their concerns related to the lack of action, bureaucracy, corruption, discriminatory practices or refusal to comply with the CRPD.

Recommendations from OPDs to governments

When asked to provide recommendations to improve this, responses covered a wide range of issues, including general recommendations for CRPD implementation. To enhance their participation in decision-making, OPDs specifically flagged the following:

- **The need for financial support**: This clearly a clear demand from a large number of OPDs. This goes beyond financial support to take part in consultation/ decision-making mechanisms. As mentioned above, OPDs also flag the lack of resources to exist and operate as civil society organisations:

The Government should fund DPOs to ensure they are appropriately resourced to undertake the consultation, advice and co-design required to enable the Government to fulfil Article 4.3 of the CRPD.
— Survey respondent from New Zealand.

The government provides limited support with funding. But this is not what we want. We want financial and technical support so that we can fully engage with partners and in programs that affect our lives.
— Survey respondent from an OPD active in several African countries.

(The government should provide) Regular and stable funding for the operation of Disability Organizations.
— Survey respondent from Slovenia.

- **A demand for diversity and inclusion** of all groups, or specific groups of persons with disabilities considered underrepresented (83 respondents)[43]. While it is clear that not all groups are at the table, greater diversity is also a demand from OPDs themselves, with demands for more balanced and equal representation, regardless of disability constituencies, level of work or size of the organisation.

Make consultations and invite all constituencies, not just the traditional ones. Make sure that persons with disabilities are having the opportunity to participate, that everything is the most accessible as possible and that reasonable accommodations are provided. If you have a parent's group and a DPO representing the same constituency, give preference to the DPO.
— Survey respondent from Brazil.

Support DPOs to consult with and represent the needs of their diverse membership, with particular consideration to the needs of people who are indigenous or culturally diverse, women, children or aged.
— Survey respondent from Australia.

- **A demand for higher degree of consideration and shared decision making**: OPDs want to be consulted, want to contribute to decision-making (74 respondents); they demand more structured and formal participation, strengthened collaboration or partnerships; they want to be listened to. OPDs identify the risks of tokenism or co-optation, and demand meaningful participation.

Listen to us, even if it takes time!
— Survey respondent from Sweden.

Sit persons with disabilities and their families at the working table, listen to what they have to say, and not to decide for them.
— Survey respondent from Argentina.

Often, they have made up their decisions, we are just invited to the 'consultations' to make it look better for the government.
— Survey respondent from Togo.

Working in a structured way to ensure that persons with disabilities and their representative organization are fully and effectively involved.
— Survey respondent from Kenya.

- **Greater participation of OPDs at different stages of the policy and programme cycle and on all relevant issues and considering disability as a cross-cutting issue** (91 respondents): in the planning, monitoring and evaluation, in the implementation, and in budget. Being able to contribute and influence from the onset is a clear demand.

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43   Children with disabilities (13), deaf persons (13), persons with intellectual disabilities (8), women with disabilities (6), persons who are hard of hearing (6), indigenous persons with disabilities (4), persons with deafblindness (4), and were mentioned explicitly.

If Governments do not, in their public policies, incorporate strategies that guarantee full inclusion in development programmes, people with disabilities will remain marginalised and side-lined, and the SDGs, like the MDGs, will fail to improve their situation.
— Survey respondent from Mauritania.

- **Accessibility and reasonable accommodation** is a key demand as preconditions for equal participation in decision-making, and more generally in society. OPDs call for holding of consultation in accessible venues (including accessible transportation to the venue), with information and communication provided in accessible formats; they demand accessibility of information and communication during meetings, provision of reasonable accommodation and alternative modes such as online consultation, simplification of content, processes and methods:

It's important to work on capacity building and make the participation of the civil society meaningful trough 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.

(…) There is only one way how to be even partly involved in the government work, but rules are too strict, that some people with disabilities are not able to fulfil them. We are not able. We sometimes send our demands through other organizations, but we think we are not considered either.
— Survey respondent from the Czech Republic.

- Respondents also recommended that **governments should enhance their own capacity to be inclusive**, including by hiring more persons with disabilities, especially at functions relating to disability issues, and training their personnel on the rights of persons with disabilities and on how to engage with persons with disabilities:

All government employees at all levels should be trained on accessibility criteria and reasonable adjustments to guarantee effective participation of people with different types and degrees of disabilities– survey respondent from Peru Support OPDs with capacity building and training: OPDs also demand support to increase their capacity to engage meaningfully as credible interlocutors from their government, with resources to channel the priorities of persons with disabilities from the local level up, and knowledge of how to engage in building public policies. Increase investment in capacity building of DPOs for greater engagement and inclusion.
— Survey respondent from Kenya.

Provide training to social organizations and promote and build leadership capacity that represents a whole country at local, national and international events.
— Ssurvey respondent from Venezuela.

5

Participation of Organizations of Persons with Disabilities with the United Nations

Key findings:

- While 44% of OPDs reported being involved with the United Nations, t**hey are overall not familiar with their work**, including 23% who are not able to identify the entity.
- Among UN entities, **UNICEF and UNDP** are identified by OPDs as the most inclusive agencies.
- **The UNPRPD is clearly perceived as comparatively more inclusive of OPDs** than UN entities selected by OPDs as the most inclusive, at all stages of the cycle – with the exceptions of budget decisions and governance and decision-making which are at similar levels.
- **A majority of OPDs who do engage with the UN report that their experience is positive**: 54% consider it good or very good, while 27% consider it mixed and 19% poor or very poor. OPDs who report their experience of engagement with the UN as good or very good mention examples of support to influence legislation, to improve national data collection, to take part in elections, or engage in training and conferences. OPDs who report poor or very poor experience with the UN shared examples of unequal participation in processes where their views are actually ignored, or experiences of the UN supporting work that they consider contravene the CRPD.
- **OPDs demand more and accessible information about the UN and their work, more substantial and regular engagement of the UN on disability issues, more engagement with OPDs**, covering underrepresented groups of persons with disabilities, and with less centralised approaches.

UN entities that ODPs are involved with

Across many questions, the high number of respondents who indicated they don't have information or are not sure about their relationship with the United Nations indicates that overall, they are less involved than with their governments. When asked if they work with the United Nations (UN), OPDs 44% reported they do engage with either formally (19%) or in informal ways (25%), while 10% clearly stated they don't at all. Comments also suggest that for many OPDs, the UN is identified with international-level entities or mechanisms only, such as the CRPD Committee or the High-Level Political Forum, but that they do not engage much at other levels.

The UN agencies have no institutionalised formal links, partnerships or communication channels with DPOs. Where contact exist, it is through government-UN links.
— Survey respondent from a regional OPD active in Africa.

Among those involved with the UN, a large percentage of respondents (23.2%) indicate that they are not sure which agency or programme of the UN they are involved[44]. This suggests **that for a wide range of OPDs, interaction with the UN is still limited, and when it exists, agencies are not necessarily well identified**. UNDP, UNICEF, WHO and OHCHR appear on the top of the list of agencies identified as involving OPDs. It is interesting to note that there are a relatively high number of responses (36) of

organisations of persons with disabilities who report they are involved with the UN Partnership on the Rights of Persons with disabilities (active in 39 countries as of the time during which the Survey was open for response).

When asked about the UN agency or programme they consider the most inclusive, UNICEF and UNDP are clearly singled out by respondents as the most inclusive agencies (see other entities mentioned by OPDs in Table 16 below).

Table 16 – UN agencies considered the most inclusive by OPDs.

UN AGENCIES CONSIDERED MOST INCLUSIVE BY OPDS:	NUMBER OF RESPONSES	%
UNICEF	21	26,9%
UNDP	19	24,4%
UN Women	8	10,3%
WHO	8	10,3%
ILO	7	9,0%
OHCHR	7	9,0%
ESCAP	2	2,6%
Committee on the Rights of Persons with Disabilities	2	2,6%
UNFPA	2	2,6%
UNESCO	2	2,6%

44 Further assessment is required to determine if this may be explained by an issue with the questionnaire itself (e.g. related to skip option) or if it reflects the fact that respondents make little difference between UN entities.

Involvement of OPDs with the UN across stages of the programme cycle

Information collected on OPDs' involvement with the UN shows the lowest levels concern budget decisions (similarly to OPDs' engagement with governments) and governance and decision making.

Because of the unique role of the UN Partnership on the Rights of Persons with Disabilities (UNPRPD) as the only UN programme fully dedicated to advancement of the CRPD, the Global Survey included specific questions to learn about OPD engagement with this fund. **The UNPRPD is clearly perceived as comparatively more inclusive of OPDs** than the UN entity selected by OPDs as the most inclusive, at all stages of the cycle – with the exceptions of budget decisions and governance and decision-making which are at similar levels.

Figure 18 – Stages of the programme cycle at which OPDs are involved with the UN entity they consider the most inclusive and with the UNPRPD.

■ With the UNPRPD   ■ With the UN agency considered the most inclusive
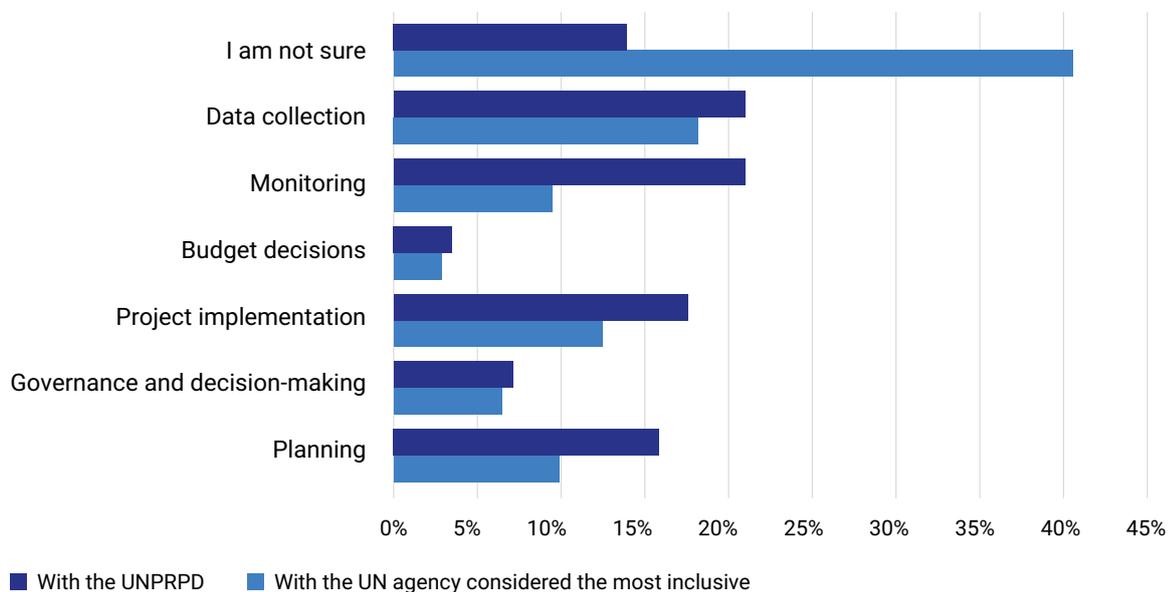
Table 17 – Stages of the programme cycle at which OPDs are involved with the UN entity they consider the most inclusive and with the UNPRPD.

INVOLVEMENT OF DPO WITH THIS UN ORGANISATION OR PROGRAMME	■ WITH THE UNPRPD	■ WITH THE UN AGENCY CONSIDERED THE MOST INCLUSIVE
In the planning of a project	**16%**	**10%**
In governance and decision-making	**7%**	**7%**
In carrying out a project	**18%**	**12%**
In budget decisions	**4%**	**3%**
In checking results and achievements (monitoring)	**21%**	**9%**
In information collection	**21%**	**18%**
I am not sure	**14%**	**41%**

Preconditions for participation of persons with disabilities ensured by the UN

Preconditions for participation are considered ensured in some ways, similar to governments or funding agencies. Worth noting within the UN system, the UNPRPD is considered better at ensuring the preconditions to participation, as compared to other UN entities selected as the most inclusive by OPDs[45]. On average, 39% of respondents said these preconditions are fully ensured by the UNPRPD, against only 21% for other UN entities[46]. The difference is particularly higher in terms of positive attitudes and knowledge of how to ensure participation of persons with disabilities, which are human factors the UNPRPD may influence more easily than accessibility, since agencies involved in implementing projects funded by the UNPRPD at country level may use venues and facilities managed by the whole UN.

While much progress remains to be made, it is worth noting some positive appreciation of improvements by the UN, as underlined by this respondent from Nigeria:

So far so good, the UN organisations has really improve in terms of accessibility, their knowledge on reasonable accommodation have increase and there is great difference from the past to the present time in the way they deal with persons with disabilities.
— Survey respondent from Nigeria.

Figure 19 – Preconditions for meaningful participation of persons with disabilities in the work of the UN entity considered the most inclusive.

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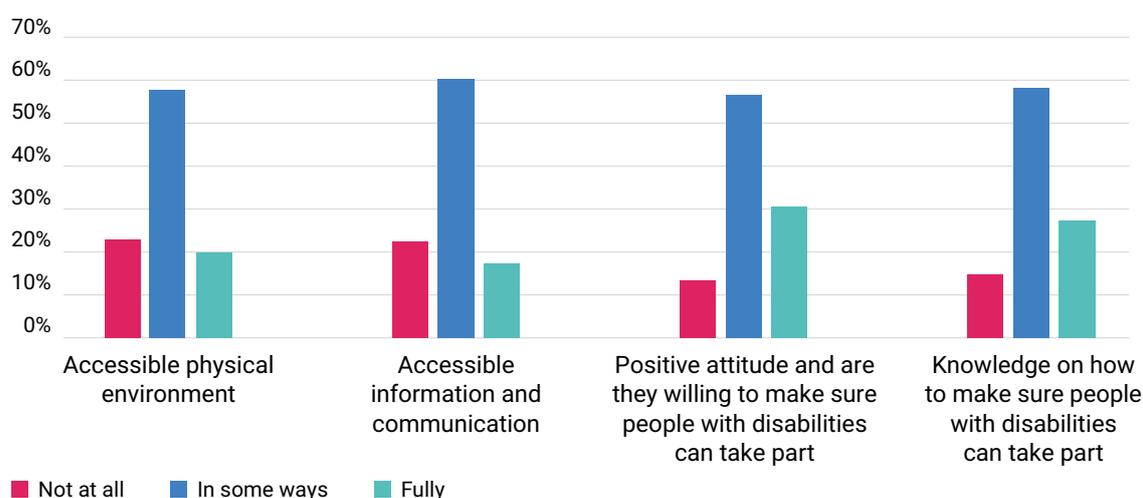
45 Respondents were asked to comment more specifically on the preconditions ensured by the UN entity they consider the most inclusive

46 The high numbers of respondents who selected 'I am not sure' and commented that they do not work with the UN suggests that there was a technical issue with the skip option of the survey. Therefore, these diagrams do not include this set of responses which would artificially increase the gap between the UNPRPD and other UN entities.

Table 18 – Preconditions for meaningful participation of persons with disabilities in the work of the UN entity considered the most inclusive.

UN AGENCY SELECTED AS MOST INCLUSIVE	ACCESSIBILITY OF THE PHYSICAL ENVIRONMENT	ACCESSIBILITY OF INFORMATION AND COMMUNICATION	POSITIVE ATTITUDES	KNOWLEDGE OF HOW TO ENSURE PARTICIPATION
Not at all	23%	23%	13%	15%
In some ways	58%	60%	56%	58%
Fully	20%	17%	30%	27%

Figure 20 – Preconditions for meaningul participation of persons with disabilities in the work of the UNPRPD.
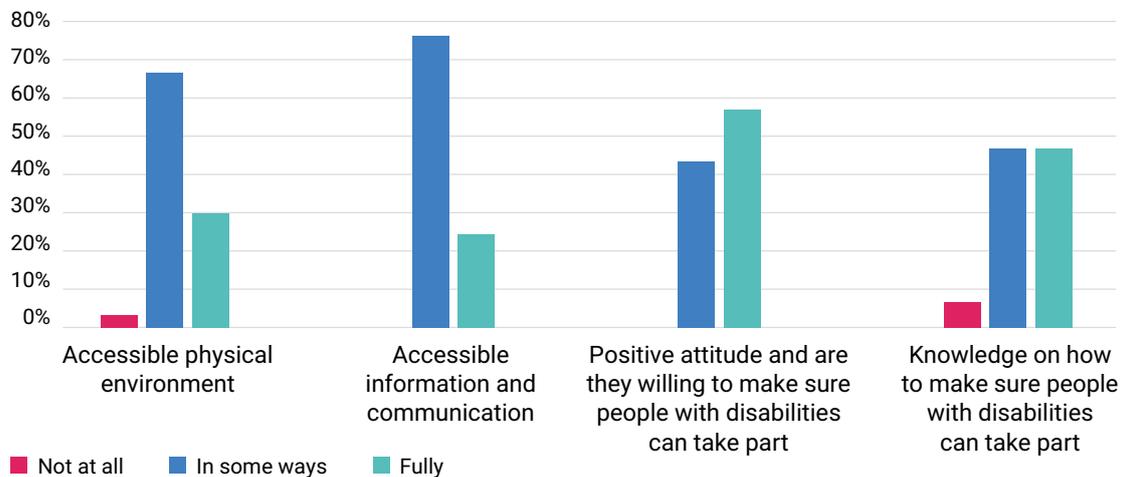
Table 19 – Preconditions for meaningul participation of persons with disabilities in the work of the UNPRPD.

UNPRPD	ACCESSIBILITY OF THE PHYSICAL ENVIRONMENT	ACCESSIBILITY OF INFORMATION AND COMMUNICATION	POSITIVE ATTITUDES	KNOWLEDGE OF HOW TO ENSURE PARTICIPATION
Not at all	3%	0%	0%	7%
In some ways	67%	76%	43%	47%
Fully	30%	24%	57%	47%

Overall satisfaction and experience of OPDs working the UN

Experiences of OPDs in engaging with the UN are limited. However, a majority of OPDs who do engage with the UN report that their experience is positive: 54% consider it good or very good, while 27% consider it mixed and 19% poor or very poor. Results are much clearer for the UNPRPD, with over 66% of respondents who are either totally pleased or overall pleased with small changes needed.

Figure 21 – Satisfaction of OPDs with their engagement with the UN and with the UNPRPD.
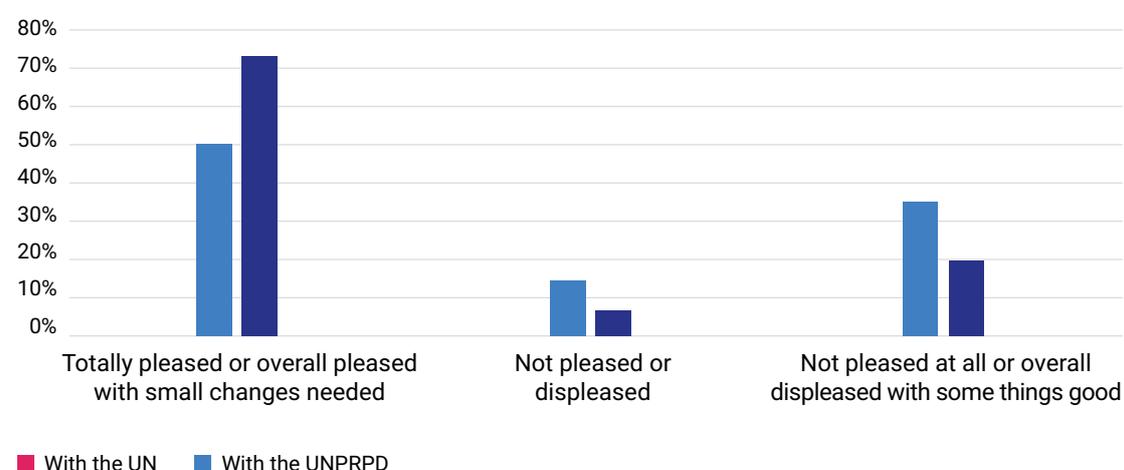
Table 20 – Satisfaction of OPDs with their engagement with the UN and with the UNPRPD.

SATISFACTION OF OPDS WITH THEIR ENGAGEMENT	WITH THE UN	WITH THE UNPRPD
Totally pleased or overall pleased with small changes needed	50,60%	73,33%
Not pleased or displeased	14,29%	6,67%
Not pleased at all or overall displeased with some things good	35,12%	20,00%

OPDs who report their experience of engagement with the UN as good or very good mention **examples of support to influence legislation, to improve national data collection, to take part in elections, or engage in training and conferences**.

Our views were taken seriously and members of the Committee took time and trouble to interact with us.
— Survey respondent from South Africa (experience considered very good).

UNDP gave immense support in Every manner possible to unsure passage of PLWD rights bill passage and involvement in Electoral processess.
— Survey respondent from Nigeria (experience considered very good).

UNDP conducted separate training for blind and visually impaired people, providing transportation, accommodation and escorts (though for a group) that resulted in raising the awareness among the blind and visually impaired people about their voting and other political rights besides the knowledge about right ways of voting. Returning back, they oriented their friends, families and relatives about the same.
— Survey respondent from Nepal (experience considered very good).

Others who have mixed experiences mention **positive engagement hindered by lack of reasonable accommodation, involvement but without a significant role**:

We are involved as interviewees just to share our thoughts, not so much as experts (…). UNDP sometimes assists us in receiving the drafts that the government is otherwise unwilling to share, also with getting our recommendations across, however UNDP has never negotiated their recommendations and view with us. (…) They have never used their authority to promote the critical opinions of independent DPOs.
— Survey respondent from Georgia (experienced considered mixed).

UNOG was supportive but not at all aware of the needs of sign language users, especially on the technical level (when trying to webcast & use more than one sign language).
— Survey respondent from Switzerland (experienced considered mixed).

Finally, OPDs who report poor or very poor experience with the UN shared **examples of unequal participation in processes** where their views are actually ignored, or **experiences of the UN supporting work that they consider contravene the CRPD**:

We have served as an expert to the UN Global Study on Children Deprived of Liberty. That program has not had adequate disability representation, it has ignored our recommendations, and it is about to publish a report directly contrary to the requirements of the CRPD. The whole process appears to be dominated by humanitarian relief organizations with large business interests in the outcome. True stakeholders, including children and adults with disabilities, are not well represented. We were ignored. Disability perspective ignored. Recommendations of UN agency, including a member of the Committee on the Rights of the Child, disregarded the requirements of the CRPD.
— Representative from an OPD working at international level (experience considered very poor).

When amending the draft law on disability rights, we have to advocate against provisions proposed by UNDP. They recommended a new definition of disability, which was not in line with UN CRPD. And the Ministry of Social Affairs and Labour supported their definition, just because they are an international organization.
— Survey respondent from Armenia (experience considered poor).

Recommendations from OPDs to the UN

As OPDs appear to not be very familiar with the work of the UN (which is sometimes only identified to the UN CRPD), there is a clear **demand for more and accessible information about the UN and their work**, including the UNPRPD.

We need to know what UN agencies and program are running in our country/part of country and how to get involved and influence to ensure that program is inclusive.
— Survey respondent from an OPD active in several regions.
A Governmental body is approached. It identifies the selected organisations. We only know about what happens from the media.
— Survey respondent from Jordan (about UNPRPD).

Global Survey respondents also identify a role for the UN to provide financial and technical assistance to OPDs to help them in advocacy, collecting robust data and monitoring. They perceive the substantial leverage they can bring to influence governments if they engage on disability issues, to demand CRPD compliance and support law enforcement.
OPDs recommend **more substantial and regular engagement of the UN on disability** in development and humanitarian issues, to avoid dependency on a few committed individuals, or ad-hoc engagement. In this regard, they also **demand that the UN engage much more with OPDs**, to provide them with more opportunities for direct funding, partnership and participation in joint projects, involvement in structured and formal mechanisms for consultation and open dialogue. Capacity building is another expectation,

with the provision of training on public policy issues, such as SDG monitoring, social protection, disability data, resource mobilisation.
This supports the findings of the Special Rapporteur on the Rights of Persons with Disabilities in her report to inform the development of the UN system policy, action plan and accountability framework to strengthen system-wide accessibility and mainstreaming of the rights of persons with disabilities[47].

DPOs are very key in development work because disabled people are often excluded in policy formulation. Again, indirect funding does not allow DPOs to operate and take ownership. The UN should develop a direct line approach to funding advocacy action plans of DPOs. No one does it better than we can do it ourselves. Women with disabilities are not left out. DPOs, when directly funded and trained, will carry out inclusive plans for all persons with disabilities.
— Survey respondent from Nigeria.

(We recommend that the UN) prioritize the empowerment of persons with disabilities and support their work.
— Survey respondent from Armenia.

There was a decline in resources, there was only one contact person left with a small budget, and this «abandonment» left us very concerned because the support of the UN always made us stronger and has given us guidance.
— Survey respondent from Paraguay.

47 The Special Rapporteur noted in particular that "Clear gaps in mainstreaming disability inclusion exist across all pillars of the UN system at all levels, demonstrating a lack of coherent and comprehensive approaches", UN Disability Inclusion Strategy, 2019.

(We recommend) that the UN requires national governments to pay for the services of comprehensive assistants or interpreter guides for persons with deafblindness or other disabilities to improve the quality of life and the participation of all OPDs in all activities. That our voice be heard directly at the UN.
— Survey respondent from Venezuela.

Invite DPOs in the Needs Assessment and Strategic Planning sessions of UN Agencies to avoid small punctual support without palpable impact.
— Survey respondent from the Democratic Republic of Congo.

Support to conduct and monitor compliance with local and international laws. Contributing to the creation of a 33 (2,3) article necessarily involving DPOs.
— Survey respondent from Azerbaijan.

Engagement of the UN with OPDs should **cover all groups of persons with disabilities**, in particular underrepresented groups, and demand pathways for engagement of a diverse range of OPDs.

There is also a demand for **less centralised approaches** from the UNPRPD, as persons with disabilities in rural areas are rarely given the chance to participate.
For people with disabilities in rural areas nothing is accessible.
— Survey respondent from India
about the UNPRPD).

Once again the UN should decentralize their work at the grass roots for first-hand information.
— Survey respondent from Uganda
(about the UNPRPD)

6 Participation of organisations of persons with disabilities with funding agencies

Key findings:

- OPDs overall engage less with funding agencies than with their governments. When they do, they engage a bit more with INGOs focused on disability, followed by governmental agencies and foundations. **They are very rarely involved with mainstream NGOs**, humanitarian actors or development banks, which testifies to gaps in addressing the rights of persons with disabilities as a cross-cutting issue, by mainstream actors and not only entities with a focused disability mandate.

- **OPDs engaged with funding agencies report positive experiences** (66%), enabling access to funding and technical guidance such as for policy change. However, some report frustrating experiences of being invited while projects are implemented by others, and some groups such as persons with psychosocial disabilities and persons with intellectual disabilities being excluded.

- Trends in increasing financial resources of OPDs tend to confirm the overall positive momentum towards greater involvement of OPDs, with **32% of OPDs reporting their funding increased or increased a lot as compared to one year ago**.

Funding agencies that ODPs are involved with

A relatively large percentage of respondents (19%) indicated they don't have information to answer this question and 13% that they are sure they don't. OPDs who indicate working with funding agencies are twice more to have formal relationships, such as being project partners or part of committees.

OPDs engage more frequently with:
- **International non-governmental organizations (INGOs) focused on disability (12.6%)**
- Government funding agencies (9.6%)
- Foundations (9.6%)
- International non-governmental organizations (INGOs) not focused on disability (5.1%)
- Humanitarian actors (3.1%)
- Development banks (1.4%)

Respondents singled out CBM and the Disability Rights Fund (DRF) (each mentioned 17 times) as the most inclusive funding agencies. These are followed by a group of agencies mentioned 6 to 10 times including USAID (10), Humanity & Inclusion (9), DFID (9), CBR Forum (9), the European Union/European Commission (8), Sightsavers (7), DFAT/Australian Aid (6) and Open Society Foundation (6). Another group of agencies was mentioned 2 to 5 times each (GIZ, Liliane Foundation, IDA, Abilis Foundation, Royal Commonwealth Society, UN Women, the World Bank, RIADIS, Action Aid, UNDP and ICRC) and 54 other funding agencies are mentioned once.

Involvement of OPDs with funding agencies across stages of the programme cycle

With the funding agency that they consider the most inclusive, **OPDs report that they are primarily involved in implementation of projects**. Comments suggest that their relationship is either through receiving funding (which they implement) or attending major conferences and celebrations – with limited roles, but not really in influencing decision-making processes. There are very few comments concerning participation of OPDs in shaping donor policies, with the exception of DFAT's Development for All policy.

They just invite us for the participation in conference or organize conference, meeting with DPOs based in Capital city Islamabad. Or project proposal implemented in other parts of the country. Overall DPOs are excluded.
— Survey respondent from Pakistan.

We are invited when projects are put forward but they are implemented by other parties. We are sometimes invited to the final ceremony at the completion of the funded projects undertaken by other organisations.
— Survey respondent from Jordan.

As noted previously, 73% of OPDs responded that they work with funding agencies in relation to disability issues. Over a third of OPDs are involved with funding agencies on education, health and employment, and over 20% are involved on gender equality, social protection, poverty reduction, participation in political life and access to justice.

Access to funding and experience of OPDs with funding agencies

Overall, OPDs are very positive about their engagement with funding agencies. Among experiences reported as good or very good, examples provided account for **opportunities to access funding** (sometimes in the longer run), **grow technical and organisational capacities**, involvement across from design to implementation, support to policy change, technical guidance and support to understand how international cooperation works.

(We) get involved at the project design stage, so local DPOs can understand how to transfer our needs into an international project and the logic behind.
— Survey respondent from China.

(About DFAT and EU) Their support promotes disabled people's rights and development. It also helps to promote awareness and leaders' perceptions and policy.
— Survey respondent from Bangladesh.

Among those with mixed, poor or very poor experiences, examples refer to **limited success with funding, changed decisions on funding, having to claim funding, gaps in ensuring accessibility or reasonable accommodation or neglect for certain groups**, in particular persons with intellectual disabilities and persons with psychosocial disabilities:

The government initially accepted the funding before reversing its decision. Finally, under pressure from the various disability stakeholders, they agreed to finance the event.
— Survey respondent from New Caledonia.

(We) advocated for them to fund organizations working with persons with intellectual disability and/or development disabilities but they were not willing to allocate funding to this area. They said they worked with disability already (deaf, blind and physical).
— Survey respondent from Uganda.

Eventually, the Global Survey also captured information about **partnerships of OPDs with universities or research organisations**, which show a relatively large degree of collaboration: almost 26% report working systematically or regularly with them, 37% sometimes, and 22% that they don't.

Trends in increasing financial resources of OPDs tend to confirm the overall positive momentum towards greater involvement of OPDs, with 32% of OPDs reporting their funding increased or increased a lot as compared to one year ago.

Figure 22 – OPD perception of the evolution of their funding, as compared to one year ago.
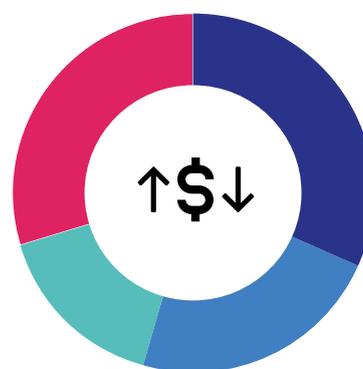
Percentage of evolution:

● **It increased or increased a lot: 32%**

● **It stayed the same: 23%**

● **It reduced a small amount or a lot: 16%**

● **I am not sure: 30%**

Although this brings a positive signal, this should not undermine the clear message coming out across survey sections that **OPDs are largely under-resourced to perform their work** in good conditions, including being independent and autonomous.

Comments of this nature are numerous in the last question of the survey where respondents were given an opportunity to share 'any' comments on the topic of the survey. A negative circle exists whereby the lack of funding leads to a lack of exposure to opportunities to secure funding.

Some DPOs have good projects which lack in funding as a result of lack in exposure.
— Survey respondent from Kenya.

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.

IDA's experience is also that tight organisational requirements and due diligence for obtaining funding excludes OPDs from accessing the resources through which they could strengthen their organisational capacity. Through the GLAD network, the donor community started to acknowledge that OPDs need more support from governments and donors to build their capacity to deliver on new agendas[48].

What OPDs think of their own roles

Although this was not the primary purpose of the survey, responses tell us also a lot about what OPDs think of themselves and their roles. The survey shows a strong sense of the unique and indispensable perspective and expertise they can bring as organisations representing the lived experiences of persons with disabilities. Yet they are 'still not recognized as experts' (survey respondent from Nepal).

DPOs should be united and develop solidarity to each other in common issues. For the specific issues, they need to do strong advocacy separately if needed.
— Survey respondent from Nepal.

DPOs have a critical role to play. Their empowerment resulting in participation is key to assess the need and plan development programmes and policies. They will be leading their respective communities to their rights realisation eventually.
— Survey respondent from India.

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.

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48   GLAD network, Communique: **GLAD Network meeting in Washington DC, 3 to 5 February 2020**

Conclusions and recommendations

Key findings from the IDA Global Survey

This initial IDA Global Survey provides for the first time at this scale an impression of the experience of organisations of persons with disabilities (OPDs) with regards to their participation in policies and programmes with different stakeholders. As such, this report provides 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 (Article 4.3), including through international cooperation (Article 32).

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.
- **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.
- **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.
- **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.
- **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.

- **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.
- **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.
- 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.
- **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 or being invited to legitimize a process, without their view being adequately considered.

Increasingly consulted, but not yet participating: IDA's recommendations for meaningful participation of OPDs

This section presents the recommendations from IDA drawing from the wealth of information shared through this survey, including recommendations shared by respondents themselves. They also strongly draw from the recommendations already shared by the CRPD Committee in General Comment 7[49], as well as members and partners who actively support OPD participation.

I am pleased with the progress in these areas, but it seems like we have a long way to go.
— Survey respondent from an OPD active in several regions.

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).

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49   General Comment 7. In particular, Section V/ para. 94

While there are indicators of overall positive trends towards more participation of OPDs, much remains to be done. Sharing information does in itself constitute inclusion or meaningful participation.

Involving OPDs solely for consultation and without the opportunity to engage concretely in decision-making activities does not constitute meaningful involvement[50]. OPDs demand to be listened to and to be part of decision-making (involvement and co-decision)[51].

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 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; accessibility and reasonable accommodation should be provided in different processes and tailored to ensure the participation of those persons with disabilities who are often marginalized, for instance, providing persons with psychosocial and intellectual disabilities with adequate supported decision making. Meaningful participation also includes efforts to create an environment that is conducive to effective contributions. OPDs indeed have limited organisational, financial and/or technical resources, and meaningful engagement in any process generates strong opportunity costs in terms of time and human resources[52]. 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.

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50 European Disability Forum (2019). Guidance Note on the Role of European organisations of persons with disabilities in International Cooperation.

51 In this regard, the Ford Foundation proposes an interesting typology, in: Framework for participatory grantmaking, quoted in Gibson, S. and al (2018). Deciding together, shifting power and resources through participatory grantmaking. Grantcraft, a service of Foundation Centre.

52 This is also a conclusion of 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, supported decision making, 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 including representation of local level. 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 (for example through annual consultations), 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[53].

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 budgets available for accessibility and reasonable accommodation. Where relevant, condition UN funding to projects that entail clearly resourced OPD participation in projects.

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53 European Disability Forum (2019). Guidance Note on the Role of European organisations of persons with disabilities in International Cooperation.

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**[54], 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 their access by ensuring application processes and requirements are accessible and proportionate to the realities of different size and capacity of OPDs. Where administering small grants is an administrative burden, 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.

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54 Indicator 5: Systematic close consultation with and active involvement of, organizations of persons with disabilities on all disability-specific issues and broader issues, UN Disability Inclusion Strategy, 2019.

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**[55]. 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 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 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. **ngage with the Global Action on Disability (GLAD) network to learn and share good practices** about effective ways of engaging with OPDs in donors' work.

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55 Gibson, S. and al (2018). [Deciding together, shifting power and resources through participatory grantmaking](). **Grantcraft, a service of Foundation Centre.**

References

Buettgen, A., Hardie, S., Crawford, C., Mounier, E., & Grisim, K. (2020).
Independent Evaluation of IDA's Disability Catalyst Programme: Realising the rights of persons with disabilities through the SDGs.
Canadian Centre on Disability Studies Incorporated operating as Eviance.

Cote, A. and al (2020).
The unsteady path towards meaningful participation of persons with disabilities.
Bridging the Gap Project. Available: https://bridgingthegap-project.eu/wp-content/uploads/The-unsteady-path.-A-pilot-study-by-BtG.pdf

European Disability Forum (2019).
Guidance note on the role of European organizations of persons with disabilities in international cooperation.
Available: http://www.edf-feph.org/newsroom/news/edf-launches-guidance-note-role-dpos-international-cooperation

Gibson, S. and al (2018).
Deciding together, shifting power and resources through participatory grantmaking.
Grantcraft, a service of Foundation Centre.
Available: https://grantcraft.org/content/guides/deciding-together/

Löve, L., Traustadóttir, R., Quinn, G., Rice, J. (2017).
The inclusion of the lived experience of disability in policymaking.
Laws, MDPI, Open Access Journal

Office of the United Nations High Commissioner for Human Rights (2006).
Principles and Guidelines for a Human Rights Approach to Poverty Reduction Strategies.
HR/PUB/06/12

Ravitch, SM., Mittenfelner Carl, N. (2016).
Qualitative research: Bridging the conceptual, theoretical, and methodological.
Thousand Oaks, CA: Sage.

United Nations, 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. CRPD/C/GC/7

United Nations General Assembly (2007).
Convention on the Rights of Persons with Disabilities. A/RES/61/106

United Nations General Assembly, Human Rights Council (2016).
Report of the Special Rapporteur on the rights of persons with disabilities. A/HRC/31/62

UN Human Rights Council (2017).
Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. A/HRC/35/21

United Nations (2019).
United Nations Disability Inclusion Strategy.
Available: https://www.un.org/en/content/disabilitystrategy/assets/documentation/UN_Disability_Inclusion_Strategy_english.pdf

Walton, D. (2019).
How well is aid targeting disability?
Development Initiative as part of the Inclusive Futures programme.
Available: http://devinit.org/post/well-aid-targeting-disability/

Walton, D. (2020).
Disability-inclusive ODA: aid data on donors, channels, recipients. Development Initiatives.
Available: https://devinit.org/resources/disability-inclusive-oda-aid-data-donors-channels-recipients/

Annex 1: Survey Questionnaire

Note:

The questionnaire comprises a total of 120 items, both open- and closed-ended; and was categorised into four main sections:

- Opening Questions: Information on respondent (6 items)
- Part 1: Information on the OPD (9 items)
- Part 2: OPD participation with government; disaggregated into local level (10 items) national level (12 items), regional level (13 items), and general (19 items)
- Part 3: OPD participation with the UN (28 items)
- Part 4: OPD participation with funding agencies (23 items)

All respondents were asked all questions in Parts 1, 3, and 4 in the questionnaire. Part 2 comprised a skip function, whereby respondents selected the level at which their organisation mainly worked (local, national, or regional) and were then automatically directed to relevant questions. Based on the level that respondents chose, they were directed to questions 10-11 (local level), questions 12-13 (national level), or to questions 14-16 (regional level); while all respondents were asked question 17 onwards in Part 2 of the questionnaire.

GLOBAL SURVEY: MONITORING HOW DISABLED PERSONS ORGANISATIONS TAKE PART IN DEVELOPMENT PROGRAMMES AND POLICIES

- This survey is about how Disabled Persons Organisations (OPDs) take part in **development** programmes and policies.
- We want to hear from Disabled Persons' Organisations (OPDs).
- Your answers to this survey are very important. You can help us understand how Disabled Persons Organisations are taking part in **development** programmes and policies .
- This will help us check that 'nothing about us is done without us', and give us the information we need to make sure governments, donors and the United Nations are including all persons with disabilities in their work.
- This survey will be done again in the future so we can see how Disabled Persons Organisations (OPDs) participation in **development** programmes and policies changes over time.
- For this survey, a Disabled Persons Organisation (OPD) is any organisation or association that is **governed** by persons with disabilities.
- Only one person from each organisation should complete this survey.

The survey is in 4 sections:

1. Information about your Disabled Persons Organisation (OPD)
2. Disabled Persons Organisation participation in the work of government.
3. Disabled Persons Organisation participation in the work of the United Nations.
4. Disabled Persons Organisation participation in the work of **funding agencies**.

There are no right or wrong answers to the survey. We are interested in what you think and your experiences.

The survey has about 50 questions. You will get only the questions that are about your situation. We think it will take you around 30-45 minutes to complete the survey.

We have tried to make sure that the survey uses language that is clear and easy to understand. This is called 'plain language'. Some of the more complicated words appear in bold letters. These words are explained below the question.

If you are confused about a question there is usually a "not sure" answer. If you don't know the answer there is usually a "don't know" answer. You can also contact us using this email: globalsurvey@ida-secretariat.org and we can help explain more.

In this first version of the survey, we also collect information about the person filling in the survey. This will only be used to check if all groups of persons with disabilities are able to complete the survey. This will help us make the survey better in the future.

Your information will be kept **confidential** and will not be used in any other way.

The survey is available in English, French, Spanish, Russian, Chinese, Arabic and International Sign.

If your language is International Sign please read the following instructions carefully.

You can answer some questions in the survey in International Sign. You can send us a video of you answering the question in International Sign.

This option is available for 15 questions. Under each of these 15 questions, it says that you can answer using video.

Video answers can only be in International Sign and NOT other sign languages.

Each International Sign Video can be up to 1 minute long.

Please name your video file as 'NameLastNameQuestionNumber'. For example, if your name is John Smith and you are uploading a video answer in International Sign to question 18, the file name of the video should be 'JohnSmithQuestion18'.

Send your International Sign video answer using WeTransfer to:
globalsurvey@ida-secretariat.org

WeTransfer is a website where you can upload videos. Once you upload a video there will be a link to the video that you can share. If you need help with using WeTransfer please email globalsurvey@ida-secretariat.org

If you are sending International Sign video answers you MUST fill the contact information at the end of the survey. This is so we can match your video answers to the rest of your answers.

Thank you for your time completing this survey.

Opening questions

In this section, your answers will help us know about the person who took the survey and check if there are missing groups of people who have not been able to fill in the survey. This will help us to make the next survey better and more accessible to all persons with disabilities.

a. Do you consider yourself to be:

A blind or partially sighted person

A person with physical impairments

A deaf person

A person who is hard of hearing or has other hearing difficulties

A person with deafblindness

A person with an intellectual disability

A person with autism

A person with a psychosocial disability

A person with short stature/ little people

A person with albinism

A person affected by leprosy

A person with a cognitive impairment

A person with epilepsy

A person with a chronic disease

A person with multiple impairments

A person without a disability

Other – please write here:

b. **Do you consider yourself to be:**

A man

A woman

Other

c. **What is your age:**

_____

d. **Are you getting any support from another person to complete this survey?**

Yes

No

e. **Have you completed the Bridge CRPD-SDGs training?**

Yes

No

f. **Please tick the box to confirm that you are:**

A member or a staff member of an organisation or association for persons with disabilities (Disabled Persons Organisation)

PART 1
INFORMATION ABOUT YOUR ORGANISATION

In this section, your answers will help us to understand who your organisation is, and where it works.

1. **What is the name of your Disabled Persons Organisation (OPD) (if you want to tell us):**

2. **What are the groups of people that your Disabled Persons Organisation (OPD) represent?**

   A blind or partially sighted person

   A person with physical impairments

   A deaf person

   A person who is hard of hearing or has other hearing difficulties

   A person with deafblindness

   A person with an intellectual disability

   A person with autism

   A person with a psychosocial disability

   A person with short stature/ little people

   A person with albinism

   A person affected by leprosy

   A person with a cognitive impairment

   A person with epilepsy

   A person with a chronic disease

   A person with multiple impairments

   Other – please write here:

3. **Which of the following groups of people are also represented by your Disabled Persons Organisation (OPD)?**

Women with disabilities

Children with disabilities

Older persons with disabilities

Indigenous persons with disabilities

None of the above

I am not sure

4. **Do you know if the Convention on the Rights of Persons with disabilities (CRPD) has been ratified by your country?** (If you are an organisation that works at a regional or global level, please think about the country where your Disabled Persons Organisation (OPD) is registered).

Yes

No

I am not sure

5. **Are you aware of any work or actions that your country's government has done on the Sustainable Development Goals (SDGs)?**

Yes

No

I am not sure

6. **In which country or countries does your organisation work?**

List of 200 countries:

7. **At which level does your organisation mainly work?**

If your organisation works at more than one level, please tick the box for the level that your organisation mostly works at. You will be sent to the questions that apply to you.

Local level

National level

Regional level

International or global level

PART 2
YOUR ORGANISATION'S WORK WITH GOVERNMENTS

8. **Does your Disabled Persons Organisation (OPD) work together with the government ?**

    Yes, in formal ways (for example working with government departments, taking part in consultations, or being part of boards or councils).

    Yes, in informal ways (for example meetings with government officials, or through phone communication).

    I am not aware of any formal or informal ways for us to work together.

    I am sure there are no formal or informal ways for us to work together

    I don't have enough information to answer this question.

9. **What have you worked with your government on? Tick all that apply to your Disabled Persons Organisation (OPD).**

    Only disability issues, for example working on laws on disability

    Other issues - please write here which issues:

    Poverty reduction

    Nutrition

    Health

    Education

    Gender equality

    Water and sanitation

    Employment

    Social protection

    Urbanization/housing

    Environment and climate change

    Access to justice

    Participation in political life

    Protection against violence

Disaster risk reduction and humanitarian action

Other – please write here:

_____

Don't know

If **local** is selected for the last question of Part 1:

10. How often is your Disabled Persons Organisation (OPD) invited to take part in work with the local authorities?

*(a) In planning **local** government work such as policies, plans, programmes or projects:

Always

Often

Sometimes

Rarely

Never

*(b) In decisions on the **local** government **budget:**

Always

Often

Sometimes

Rarely

Never

*(c) In carrying out government work, such as **local** policies and programmes:

Always

Often

Sometimes

Rarely

Never

*(d) In collecting data and information on the lives of persons with disabilities

at a **local** level:

Always

Often

Sometimes

Rarely

Never

* (e) In checking how well **local** government work is going (monitoring of **local** policies

and programs):

Always

Often

Sometimes

Rarely

Never

11. What is the role of your organisation with **local** authorities?

*(a) In the planning of **local** government work such as **local** policies, plans, programmes

or projects:

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

*(b) In decisions on the **local** government **budget:**

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

*(c) In carrying out **local** government work, such as local policies and programs:

> We decide together
>
> We are **consulted**
>
> We are told what is happening
>
> We know it is happening but are not directly told about it
>
> We know nothing about it
>
> I am not sure

*(d) In collecting data and information on the lives of persons with disabilities

> at the **local** level:

> We decide together
>
> We are **consulted**
>
> We are told what is happening
>
> We know it is happening but are not directly told about it
>
> We know nothing about it
>
> I am not sure

* (e) In checking how well **local** government work is going (monitoring of local policies

> and programs):

> We decide together
>
> We are **consulted**
>
> We are told what is happening
>
> We know it is happening but are not directly told about it
>
> We know nothing about it
>
> I am not sure

If **nationa**l is selected for the last question of Part 1:

12. How often is your Disabled Persons Organisation (OPD) invited to take part in work with the national authorities?

*(a) In the planning of **national** government work such as **national** policies, plans, programmes or projects

> Always
>
> Often
>
> Sometimes
>
> Rarely
>
> Never
>
> I am not sure

*(b) In decisions on the **national** government **budget**:

> Always
>
> Often
>
> Sometimes
>
> Rarely
>
> Never
>
> I am not sure

*(c) In carrying out **national** government work, such as **national** policies and programmes:

> Always
>
> Often
>
> Sometimes
>
> Rarely
>
> Never
>
> I am not sure

*(d) In **collecting data and information** on the lives of persons with disabilities at the **national** level:

> Always
>
> Often
>
> Sometimes

Rarely

Never

I am not sure

* (e) In checking how well **national** government work is going (monitoring of **national**

policies and programs):

Always

Often

Sometimes

Rarely

Never

I am not sure

13. What is the role of your organisation with national authorities?

*(a) In the planning of **national** government work such as **national** policies, plans,

programmes or projects:

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

*(b) In decisions on the **national** government **budget**:

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

*(c) In carrying out **national** government work, such as **national** policies

and programmes:

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

*(d) In **collecting data and information** on the lives of persons with disabilities at the **national** level:

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

* (e) In checking how well **national** work is going (monitoring of **national** policies and programs):

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

*(f) In the ways your country's government is working to achieve the **Sustainable Development Goals (SDGs)**:

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

*(g) In the ways your country's government is working to realise and monitor

the Convention on the Rights of Persons with disabilities (CRPD):

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

If **regional** is selected for the last question of Part 1:

14. Please select from the following regional organisations that you work with:

European Union

Association of South East Asian Nations (ASEAN)

Organisation of American States

African Union

Economic Community of West African States (ECOWAS)

Arab League

South Asia Association for **Regional** Cooperation (SAARC)

Commonwealth of Independent States (CIS)

Pacific Islands Forum (PIF)

Caribbean Community (CARICOM)

Other, please write here:

15. How frequently is your Disabled Persons Organisation (OPD) invited to take part in work with regional organisations ?

*(a) In the planning of **regional** work such as **regional** policies, plans, programmes

or projects:

Always

Often

Sometimes

Rarely

Never

I am not sure

*(b) In decisions on **budget** for **regional** work:

Always

Often

Sometimes

Rarely

Never

I am not sure

*(c) In carrying out **regional** policies and programmes:

Always

Often

Sometimes

Rarely

Never

I am not sure

*(d) In collecting data and information on the lives of persons with disabilities

at the **regional** level:

Always

Often

Sometimes

Rarely

Never

I am not sure

* (e) In checking how well the **regional** work is going (monitoring of **regional** policies and programs):

Always

Often

Sometimes

Rarely

Never

I am not sure

16. What is the role of your Disabled Persons Organisation (OPD) with regional organisations?

*(a) In the planning of **regional** work such as **regional** policies, plans, programmes or projects:

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

*(b) In decisions on **regional budgets**:

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

*(c) In carrying out the **regional** policies and programmes:

> We decide together
>
> We are **consulted**
>
> We are told what is happening
>
> We know it is happening but are not directly told about it
>
> We know nothing about it
>
> I am not sure

*(d) In collecting data and information on the lives of persons with disabilities

at the **regional l**evel:

> We decide together
>
> We are **consulted**
>
> We are told what is happening
>
> We know it is happening but are not directly told about it
>
> We know nothing about it
>
> I am not sure

* (e) In checking how well **regional** work is going (monitoring of **regional** policies

and programs):

> We decide together
>
> We are **consulted**
>
> We are told what is happening
>
> We know it is happening but are not directly told about it
>
> We know nothing about it
>
> I am not sure

*(f) In **regional** work on the **Sustainable Development Goals (SDGs)**:

> We decide together
>
> We are **consulted**
>
> We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

*(g) In **regional** work to implement and monitor the **Convention on the Rights of Persons with disabilities**:

We decide together

We are **consulted**

We are told what is happening

We know it is happening but are not directly told about it

We know nothing about it

I am not sure

17. How much do you think that Disabled Persons Organisations (OPDs) are involved in government work as compared to other civil society organisations?

Disabled Persons Organisations (OPDs) have more opportunities to take part than other **civil society** groups

Disabled Persons Organisations (OPDs) take part equally with other **civil society** groups

Other **civil society** groups have more opportunities than Disabled Persons Organisations (OPDs)

I am not sure

18. Are people from the following groups consulted by your country's government?

Blind or partially sighted people

People with physical impairments

Deaf people

Hard of hearing people or people having other hearing difficulties

People with deafblindness

People with an intellectual disability

People with autism

People with a psychosocial disability

People with short stature/ little people

People with albinism

People affected by leprosy

People with a cognitive impairment

People with epilepsy

People with a chronic disease

People with multiple impairments

Women with disabilities

Children with disabilities

Older persons with disabilities

Indigenous persons with disabilities

None of the above

I am not sure

(b) Please share any comment you may have on the different groups of people who are involved or who are not involved:

_____

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 18 (b).

19. What support does your government give so that your Disabled Persons Organisation (OPD) can take part in its work?

Support with improving skills and knowledge of your Disabled Persons Organisation (OPD) to understand and take part in your government's work

Support to make sure that your Disabled Persons Organisation (OPD) can take part in work such as a personal assistant, captioning, Braille…

Support with funding to your Disabled Persons Organisation (OPD)

Other (please write here)

_____

_____

_____

Don't know

20. How well does your government do on making sure persons with disabilities can take part in its development work?

*(a) Is the **physical environment accessible**? (such as offices, meeting venues, toilets)?

 Fully

 In some ways

 Not at all

 I am not sure

*(b) Is information and communication **accessible**? (such as Sign Language interpretation, captioning, hearing loop or microphone systems, **accessible** documents)?

 Fully

 In some ways

 Not at all

 I am not sure

(c) Does the government have a positive attitude and are they willing to make sure persons with disabilities can take part?

 Fully

 In some ways

 Not at all

 I am not sure

(d) Does the government have the knowledge on how to make sure persons with disabilities can take part?

    Fully

    In some ways

    Not at all

    I am not sure

(e) Does the government give funding to make sure your Disabled Persons Organisation (OPD) can take part, such as money for transportation, a personal assistant, an interpreter:

    Yes

    No

    I am not sure

*(f) In general, how much does your government make it easy for **civil society** groups to take part with its work?

    Fully

    In some ways

    Not at all

    I am not sure

*(f) Please share your comments on accessibility and the adjustments that have been made to make sure everyone can take part or the barriers that stop this from happening:

_____

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 20 (f).

21. Can you please share examples of your organisation taking part in work with the government?

Your example:

a) What was the part of government you were working with?

(such as the Ministry of Employment or Ministry of Education):

_____

_____

_____

_____

b) Your experience with them was:

Very good

Good

Mixed

Poor

Very Poor

c) Please describe what happened:

_____

_____

_____

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 21 (c).

22. **Overall, as a Disabled Persons Organisation (OPD), how pleased are you with the work you have done with your government or regional organisation?**

    Totally pleased

    Some small changes needed, but overall pleased

    Not pleased or displeased

    Some things are good, but overall displeased

    Not pleased at all in any way

    I am not sure

23. **If you compare with one year ago, how do you feel the involvement of your Disabled Persons Organisation (OPD) with your government or regional organisation has changed?**

    It improved a lot

    It improved in some ways

    It stayed the same

    It got worse in some ways

    It got a lot worse

    I am not sure

24. **Compared with one year ago, how do you feel the influence of your Disabled Persons Organisation with your government or regional organisation has changed?**

    It improved a lot

    It improved in some ways

    It stayed the same

    It got worse in some ways

    It got a lot worse

    I am not sure

25. In the last year, can you think of an impact or a change to your government's work or regional organization that would not have happened without your Disabled Persons Organisation (OPD)?

No

Yes. Please give us one example below:

Please note: You can upload a video up to 1 minute long in International Sign for question 25, if you select 'Yes'.

26. Please give 3 recommendations for your government to improve the way it works with Disabled Persons Organisations (OPDs)?

Recommendation 1:

_____

_____

_____

_____

Recommendation 2:

_____

_____

_____

_____

Recommendation 3:

_____

_____

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 26.

PART 3
DISABLED PERSONS ORGANISATIONS PARTICIPATION IN THE UNITED NATIONS

In this section, we want to know about how Disabled Persons Organisations (OPDs) take part in work with the United Nations (UN).

27. **Does your Disabled Persons Organisation (OPD) work together with the United Nations (UN)?**

    Yes, in formal ways (for example working as project partners, taking part in consultations, or being part of project committees)

    Yes, in informal ways (for example meetings with United Nations officials, or through phone communication)

    I am not aware of any formal or informal ways for us to work together

    I am sure there are no formal or informal ways for us to work together

    I don't have enough information to answer this question

28. **On what issues is your organisation involved with the United Nations (UN)? Please tick all that apply to you**

    Only disability issues, for example working on laws on disability

    Other issues - please write here which issues:

    > Poverty reduction

    > Nutrition

    > Health

    > Education

    > Gender equality

    > Water and sanitation

    > Employment

    > Social protection

    > Urbanization/housing

    > Environment and climate change

    > Access to justice

Participation in political life

Protection against violence

Disaster risk reduction and humanitarian action

Other – please write here:

_____

_____

_____

I am not sure

29. In your local community, country or region is your Disabled Persons Organisation (OPD) involved with:

UNICEF (United Nations International Children's Emergency Fund)

The International Labour Organisation (ILO)

The World Health Organisation (WHO)

The Office of the High Commissioner on Human Rights (OHCHR)

UN Women

The United Nations Development Programme (UNDP)

The Office for Coordination of Humanitarian Affairs (OCHA)

Projects from the United Nations Partnership to Promote the Rights of Persons with disabilities (UNPRPD)

Other UN agencies – please write here:

_____

_____

_____

I am not sure

30. In your country, are people from the following groups invited to take part in United Nations (UN) work as partners (not as people who benefit from the work)?

(a) People taking part in work:

Blind or partially sighted people

People with physical impairments

Deaf people

Hard of hearing people or people having other hearing difficulties

People with deafblindness

People with an intellectual disability

People with autism

People with a psychosocial disability

People with short stature/ little people

People with albinism

People affected by leprosy

People with a cognitive impairment

People with epilepsy

People with a chronic disease

People with multiple impairments

Women with disabilities

Children with disabilities

Older persons with disabilities

Indigenous persons with disabilities

None of the above

I am not sure

(b) Please share any comment you may have on the different groups of people who are involved or who are not involved:

_____

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 30 (b).

31. Of the United Nations (UN) organisations or programme that you know about, which do you think is the most inclusive of persons with disabilities?

Name of the United Nation (UN) organisations or programme:

_____

_____

_____

32. **Is your Disabled Persons Organisation (OPD) involved with this United Nations (UN) organisations or programme?**

In the planning of a project

In **governanc**e and decision-making

In carrying out a project

In **budget** decisions

In checking results and achievements (monitoring)

In information collection

Other – Please write here:

_____

_____

_____

I am not sure

33. **How well does the United Nations (UN) organization or programme that you work with make sure persons with disabilities can take part?**

*(a) Is the **physical environment accessible**? (such as offices, meeting venues, toilets)?

Fully

In some ways

Not at all

I am not sure

*(b) Is information and communication **accessible**? (such as Sign Language interpretation, captioning, hearing loop or microphone systems, accessible documents)?

Fully

In some ways

Not at all

I am not sure

(c) Does the United Nations (UN) organization or programme have a positive attitude and are they willing to make sure persons with disabilities can take part?

Fully

In some ways

Not at all

I am not sure

(d) Does the United Nations (UN) organization or programme have the knowledge on how to make sure persons with disabilities can take part?

Fully

In some ways

Not at all

I am not sure

(e) Does this UN organisation or programme give funding to make sure your Disabled Persons Organisation (OPD) can take part, such as money for transportation, a personal assistant, an interpreter?

Yes

No

I am not sure

*(f) Please share your comments on accessibility and the adjustments that have been made to make sure everyone can take part or the barriers that stop this from happening.:

_____

_____

_____

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 33 (f).

34. Earlier, in question 29, you answered that your Disabled Persons Organisation (OPD) works with the United Nations Partnership to Promote the Rights of Persons with disabilities (UNPRPD). Is this work:

In the planning of a project

In **governanc**e and decision-making

In carrying out a project

In **budget** decisions

In checking project results and achievements

In collecting information about the project

Other – Please tell us here:

_____

_____

_____

I am not sure

35. How well does United Nations Partnership to Promote the Rights of Persons with disabilities (UNPRPD) do on making sure persons with disabilities can take part in its work?

*(a) Is the **physical environment accessible**? (such as offices, meeting venues, toilets)?

Fully

In some ways

Not at all

I am not sure

*(b) Is information and communication **accessible**? (such as Sign Language interpretation, captioning, hearing loop or microphone systems, accessible documents)?

Fully

In some ways

Not at all

I am not sure

(c) Does the United Nations Partnership to Promote the Rights of Persons with disabilities (UNPRPD) have a positive attitude and are they willing to make sure persons with disabilities can take part?

    Fully

    In some ways

    Not at all

    I am not sure

(d) Does the United Nations Partnership to Promote the Rights of Persons with disabilities (UNPRPD) have the knowledge of how to make sure persons with disabilities can take part?

    Fully

    In some ways

    Not at all

    I am not sure

(e) Does this UN Partnership to Promote the Rights of Persons with disabilities (UNPRPD) provide funding to make sure your Disabled Persons Organization can take part, such as money for transportation, a personal assistant, an interpreter?

    Yes

    No

    I am not sure

*(f) Please share your comments on accessibility and the adjustments that have been made to make sure everyone can take part or the barriers that stop this from happening.:

_____

_____

_____

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 35 (f).

36. **How pleased are you with how the United Nations Partnership to Promote the Rights of Persons with disabilities (UNPRPD) work with your organisation?**

Totally pleased

Some small changes needed, but overall pleased

Not pleased or displeased

Some things are good, but overall displeased

Not pleased at all in any way

I am not sure

37. **Overall, as a Disabled Persons Organisation (OPD), how pleased are you with your work with the United Nations (UN)?**

Totally pleased

Some small changes needed, but overall pleased

Not pleased or displeased

Some things are good, but overall displeased

Not pleased at all in any way

I am not sure

38. **Can you please share any experiences that your organisation has had working with the United Nations (UN)?**

(a) Your example:

What was the name of the United Nations (UN) group or programme of work:

_____

(b) This experience was:

Very good

Good

Mixed

Poor

Very Poor

(c) Please describe what happened:

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 38 (c).

39. If you compare with one year ago, how do you feel the involvement of your Disabled Persons Organisation (OPD) with the United Nations (UN) has changed?

It improved a lot

It improved in some ways

It stayed the same

It got worse in some ways

It got a lot worse

I am not sure

40. Compared with one year ago, how do you feel the influence of your Disabled Persons Organisation with the United Nations (UN) has changed?

It improved a lot

It improved in some ways

It stayed the same

It got worse in some ways

It got a lot worse

I am not sure

41. Please give 3 recommendations to Disabled Persons Organisations (OPDs) on how to improve the impact of their work with the United Nations (UN)?

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 41.

PART 4
DISABLED PERSONS ORGANISATIONS PARTICIPATION IN FUNDING AGENCIES' WORK

42. Does your Disabled Persons Organisation (OPD) work together with funding agencies?

Yes, in formal ways (for example working as project partners, taking part in consultations, or being part of project committees).

Yes, in informal ways (for example meetings with officials, or through phone communication).

I am not aware of any formal or informal ways for us to work together.

I am sure there are no formal or informal ways for us to work together

I don't have enough information to answer this question

43. Is your organisation involved with funding agencies in relation to:

Only disability issues, for example working on laws on disability

Other issues - please write here which issues:

Poverty reduction

Nutrition

Health

Education

Gender equality

Water and sanitation

Employment

Social protection

Urbanization/housing

Environment and climate change

Access to justice

Participation in political life

Protection against violence

Disaster risk reduction and humanitarian action

Other – please write here:

_____

_____

I am not sure

44. In your local community, country or region, what type of funding agencies is your Disabled Persons Organisation involved with?

Government **funding agencies**, such as The Department for International Development (DFID) from the United Kingdom, Agence Française de Développement (AFD) from France, the European Commission, Gesellschaft für Internationale Zusammenarbeit (GIZ) from Germany, United States Agency for International Development (USAID),

Foundations such as Disability Rights Fund, Open Society Foundation, Aga Khan Foundation, etc.

Development Banks such as the World Bank, the Asia Development Bank, etc.

International non-governmental organizations (INGOs) focused on disability, such as CBM, Humanity & Inclusion (erstwhile Handicap International), Sightsavers, Leonard Cheshire Disability, etc.

International non-governmental organizations (INGOs) not focused on disability, such as Save the Children, Oxfam, Plan International,

Humanitarian actors, such as the International Committee of Red Cross, the Red Cross, Medecins Sans Frontières, etc.

Not sure

45. In your country, are people of the following groups invited to take part in the work of funding agencies, as partners (not as people who benefit from the work)?

(a) People taking part in work:

Blind or partially sighted people

People with physical impairments

Deaf people

Hard of hearing people or people having other hearing difficulties

People with deafblindness

People with an intellectual disability

People with autism

People with a psychosocial disability

People with short stature/ little people

People with albinism

People affected by leprosy

People with a cognitive impairment

People with epilepsy

People with a chronic disease

People with multiple impairments

Women with disabilities

Children with disabilities

Older persons with disabilities

Indigenous persons with disabilities

None of the above

I am not sure

(b) Please share any comment you may have on the different groups of people who are involved or who are not involved:

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 45 (b).

46. Among the funding agencies that you know about, which do you think is the most inclusive of persons with disabilities?

Name **funding agency**:

_____

_____

47. **How does your Disabled Persons Organisation (OPD) work with this funding agency?**

In the planning of project work

In **governanc**e and decision-making

In carrying out project work

In **budget** decisions

In checking project results and achievements

In collecting information on the work

Other – Please write here:

I am not sure

48. **How well does this funding agency do on making sure persons with disabilities can take part in its work?**

*(a) is the **physical environment accessible**? (such as meeting venues, toilets)?

Fully

In some ways

Not at all

I am not sure

*(b) Is information and communication **accessible**? (such as Sign Language interpretation, captioning, hearing loop or microphone systems, publication in accessible formats)?

Fully

In some ways

Not at all

I am not sure

(c) Does the **funding agency** have a positive attitude and are they willing to make sure persons with disabilities can take part?

        Fully

        In some ways

        Not at all

        I am not sure

(d) Does the **funding agency** have the knowledge on how to make sure persons with disabilities can take part?

        Fully

        In some ways

        Not at all

        I am not sure

(e) Does this **funding agency** give funding to make sure your Disabled Persons Organisation (OPD) can take part it its work, such as money for transportation, a personal assistant, an interpreter

        Yes

        No

        I am not sure

*(f) Please share your comments on accessibility and the adjustments that have been made to make sure everyone can take part or the barriers that stop this from happening.:

_____

_____

_____

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 48 (f).

49. Can you please share any examples of your organisation taking part in work with funding agencies?

Your example:

(a) Name of the **funding agency**:

_____

_____

(b) This experience was:

Very good

Good

Mixed

Poor

Very Poor

(c) Please describe what happened:

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 49 (c).

50. Overall as a Disabled Persons Organisation (OPD), how pleased are you with your work with funding agencies?

Totally pleased

Some small changes needed, but overall pleased

Not pleased or displeased

Some things are good, but overall displeased

Not pleased at all in any way

I am not sure

51. If you compare with one year ago, how do you feel the involvement of your Disabled Persons Organisation (OPD) with funding agencies has changed?

It improved a lot

It improved in some ways

It stayed the same

It got worse in some ways

It got a lot worse

I am not sure

52. **Compared with one year ago, how do you feel the influence of your Disabled Persons Organisation (OPD) with funding agencies has changed?**

It improved a lot

It improved in some ways

It stayed the same

It got worse in some ways

It got a lot worse

I am not sure

53. **In the last year, how has the funding for your Disabled Persons Organisation (OPD) changed?**

It increased a lot

It increased

It stayed the same

It reduced a small amount

It reduced a lot

I am not sure

54. **Does your organisation work with universities or research organisations in your country?**

Yes, we work with them all the time

Yes, we work with them regularly

We work with them sometimes

No, we do not

Don't know

55. **Please share any final comments that you wish to add about Disabled Persons Organisation (OPD) work on development programmes and policies**

_____

_____

_____

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 55.

56. **Please share any feedback you wish to make about the accessibility or the content of this survey:**

_____

_____

_____

_____

_____

Please note: You can upload a video up to 1 minute long in International Sign for question 56.

CONTACT INFORMATION

Many thanks for taking the time to complete this survey!

The International Disability Alliance (IDA) may want to follow up with people who answered this survey about their answers.
If you are happy for us to get in touch with you, please give us your contact information in this section.

If you are uploading video answers in International Sign then you MUST give us your contact information. This will make it possible for us to match your other answers with the International Sign video answers. We will not use this information in any other way.

Your contact Information:

Name:

Email Address:

Phone Number:

The International Disability Alliance (IDA) will look at all the answers to this survey and will create a global report about the survey.

The survey will be available on our website: www.internationaldisabilityalliance.org

For more information please contact Dorodi Sharma at globalsurvey@ida-secretariat.org

Annex 2

Definitions of terms

Note:

The definitions below are part of a plain language version of the survey questionnaire. They were recommended and reviewed by self-advocates to make the survey easier to understand.

Accessible
When something is easy to use or access for everyone including persons with disabilities. For example, an accessible document is one that is produced in way that all people can read, understand, and use it.

Development work
The work that is done to improve the standards of living of the people living in a country. Development work is about making sure more people have the things they need to live a good life.

Governed/ governance
The way that organisations or countries are managed. People involved with governance make the decisions on how things are run.

Funding agencies
A group, organisation or part of a government that provides money for a particular bit of work.

Confidential
Keeping something private and not sharing it with others for any reason.

Bridge CRPD-SDGs training
Training that is organized for persons with disabilities to know about their rights and how to influence the government to realize these rights. This training is organized by the International Disability Alliance (IDA) with other partner organisations.

Indigenous
A person who is a native or originally from a particular place.

Convention on the Rights of Persons with disabilities (CRPD)
An international agreement created by the United Nations (UN). It protects the human rights of persons with disabilities.

Ratified
Sign and agree to a document such as a law, treaty, contract, or agreement.

Sustainable Development Goals (SDGs)
A global call to action by the United Nations (UN) to end poverty, protect the planet and make sure that all people enjoy peace and good lives. This plan is also known as 'Agenda 2030'.

Budget
A plan on how much money a person or an organisation has and how much they will need or be able to spend.

Consulted
When something is shared and talked about with a person or a group of people in order to get their ideas, suggestions or advice.

Local
A community, a city or a part of a country.

Regional
In a large part of the world made up of different countries, such as Europe, Africa, the Americas, and Asia-Pacific.

National
At the level of a whole country.

Civil society
A group of organisations who work to help people in society or represent their voice. Civil society organisations work independently and are not run by governments or as a private business. Organizations that make up civil society might include charities, churches, shelters, food banks and other organisations that provide a service that helps people. Disabled People's Organisations are one kind of civil society organisations.

Physical environment
The things and setting around a person, for example in a room the physical environment would be the furniture, lighting, and layout of a room. In a city, the physical environment would be the roads, buildings, parks, etc.

Influence
The power to have an effect on someone or something.

Impact
Making a change happen on someone or something.

Recommendations
Suggestions or ideas on the best way to do something.

Policy
Decisions that governments make to ensure that the laws are made real in a country.

Programme
A set of activities that is decided to make a change. For example a programme to improve access to school for children.

Evaluation
Ensuring or checking that some work has been done and what change it has made.

Monitoring
Checking how well the work is going.

Annex 3

Countries in which OPD respondents work[56]

COUNTRY	N	COUNTRY	N	COUNTRY	N
Afghanistan	4	Germany	14	Niger	4
Albania	4	Ghana	8	Nigeria	22
Algeria	8	Greece	7	Norway	12
Andorra	1	Guatemala	3	Oman	2
Angola	4	Guinea	2	Pakistan	11
Argentina	3	Guinea-Bissau	2	Palestinian Territories	2
Armenia	5	Guyana	1	Panama	5
Australia	7	Haiti	3	Papua New Guinea	1
Austria	7	Honduras	2	Paraguay	3
Azerbaijan	2	Hungary	8	Peru	3
Bahrain	1	Iceland	6	Philippines	6
Bangladesh	15	India	68	Poland	7
Belarus	3	Indonesia	6	Portugal	7
Belgium	11	Iran	2	Qatar	2
Belize	1	Iraq	3	Romania	9
Benin	1	Ireland	10	Russia	13
Bolivia	2	Israel	6	Rwanda	8
Bosnia and Herzegovina	6	Italy	10	Samoa	1
Botswana	4	Japan	3	San Marino	2
Brazil	4	Jordan	4	Saudi Arabia	2
Brunei	1	Kenya	22	Senegal	4
Bulgaria	6	Kosovo	1	Serbia	4
Burkina Faso	3	Kuwait	1	Seychelles	1
Burundi	2	Laos	1	Sierra Leone	7
Cambodia	1	Latvia	5	Singapore	2
Cameroon	10	Lebanon	5	Slovakia	2
Canada	10	Lesotho	5	Slovenia	9
Cape Verde	2	Liberia	4	Solomon Islands	1

---

56 The cumulated number of countries does not reflect the number of responses to the survey, but the number of countries in which OPD respondents work. Global and regional organisations of persons with disabilities selected multiple countries yet responded only once to the survey.

COUNTRY	N	COUNTRY	N	COUNTRY	N
Central African Republic	3	Libya	4	Somalia	3
Chad	3	Liechtenstein	2	South Africa	9
Chile	3	Lithuania	8	South Sudan	5
China	13	Luxembourg	6	Spain	9
Columbia	10	Macedonia	2	Sri Lanka	2
Congo, Democratic Republic	5	Madagascar	3	Sudan	2
Congo, Republic	2	Malawi	8	Swaziland	2
Cote d'Ivoire	6	Malaysia	1	Sweden	16
Croatia	5	Maldives	1	Switzerland	8
Cyprus	3	Mali	4	Syria	2
Czech Republic	8	Malta	7	Tanzania	11
Denmark	11	Mauritania	2	Thailand	4
Djibouti	2	Mauritius	4	Togo	5
Dominican Republic	3	Mexico	5	Tunisia	4
Ecuador	1	Micronesia	1	Turkey	6
Egypt	12	Moldova	2	Uganda	17
El Salvador	3	Monaco	1	Ukraine	6
Equatorial Guinea	3	Mongolia	2	United Arab Emirates	4
Eritrea	2	Montenegro	2	United Kingdom	12
Estonia	4	Morocco	4	United States of America	11
Ethiopia	7	Mozambique	4	Uruguay	1
Fiji	1	Myanmar	2	Uzbekistan	2
Finland	9	Namibia	4	Vanuatu	1
France	12	Nepal	12	Venezuela	7
Gabon	3	Netherlands	11	Vietnam	6
Gambia	3	New Zealand	47	Zambia	6
Georgia	11	Nicaragua	2	Zimbabwe	5

Annex 4

OPD involvement and level of shared decision-making across stages of the government policy or programme cycle

Planning

Figure a1 – OPD invitation to take part in planning of governments policies and programmes
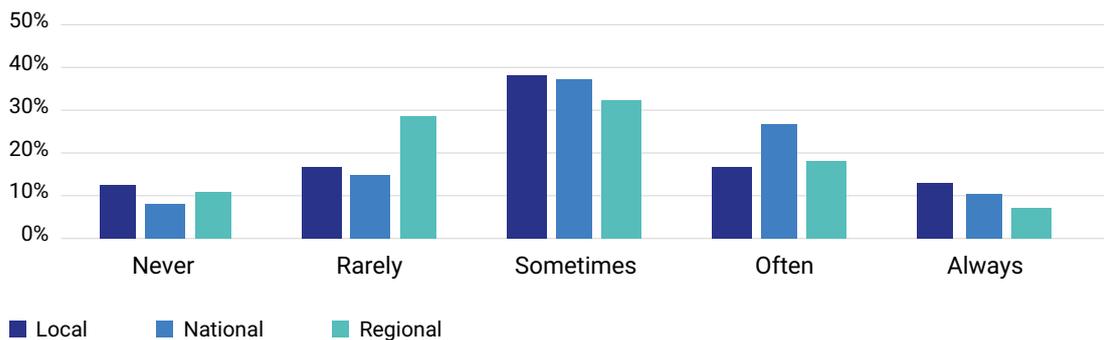

Table a1 - OPD invitation to take part in planning of governments policies and programmes

| PLANNING	LOCAL	NATIONAL	REGIONAL
Never	13%	8%	11%
Rarely	17%	15%	30%
Sometimes	40%	39%	33%
Often	17%	28%	19%
Always	13%	11%	7%
total	100%	100%	100%

Figure a2 – Level of information/ participation of OPDs in planning government policies and programmes
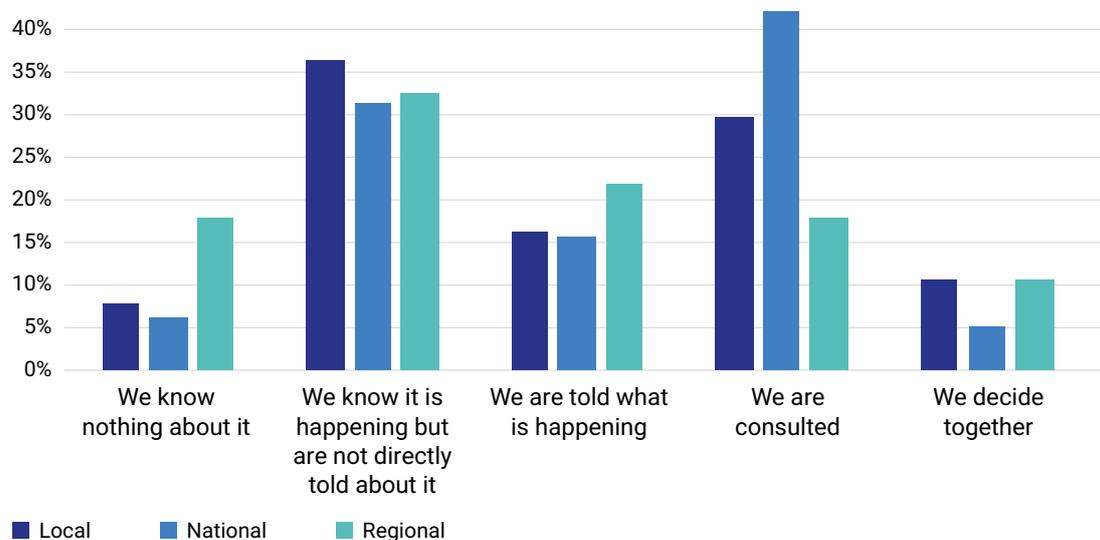
Table a2 - Level of information/ participation of OPDs in planning government policies and programmes

PLANNING	LOCAL	NATIONAL	REGIONAL
We know nothing about it	8%	6%	18%
We know it is happening but are not directly told about it	36%	31%	32%
We are told what is happening	16%	15%	21%
We are consulted	30%	43%	18%
We decide together	10%	5%	11%

Budget decisions

**Figure b1 – OPD invitation to take part in budget decisions**

Table b1 – OPD invitation to take part in budget decisions

| BUDGET	LOCAL	NATIONAL	REGIONAL
We know nothing about it	30%	27%	32%
We know it is happening but are not directly told about it	35%	34%	25%
We are told what is happening	16%	25%	18%
We are consulted	13%	12%	21%
We decide together	6%	2%	4%

Figure b2 – Level of information/ participation of OPDs in budget decisions

Table b2 – Level of information/ participation of OPDs in budget decisions

BUDGET	LOCAL	NATIONAL	REGIONAL
We know nothing about it	30%	27%	32%
We know it is happening but are not directly told about it	35%	34%	25%
We are told what is happening	16%	25%	18%
We are consulted	13%	12%	21%
We decide together	6%	2%	4%

Implementation

Figure c1 – OPD invitation to take part in implementation of government policies and programmes
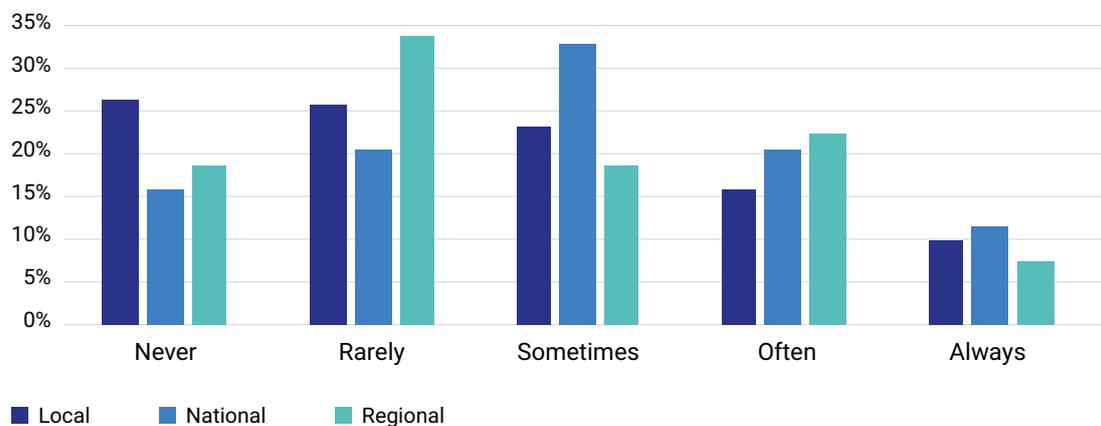

Table c1 – OPD invitation to take part in in implementation of government policies and programmes

IMPLEMENTATION	LOCAL	NATIONAL	REGIONAL
Never	26%	16%	19%
Rarely	25%	20%	33%
Sometimes	23%	33%	19%
Often	16%	20%	22%
Always	10%	11%	7%

Figure c2 – Level of information/ participation of OPDs in implementation of government programmes and policies
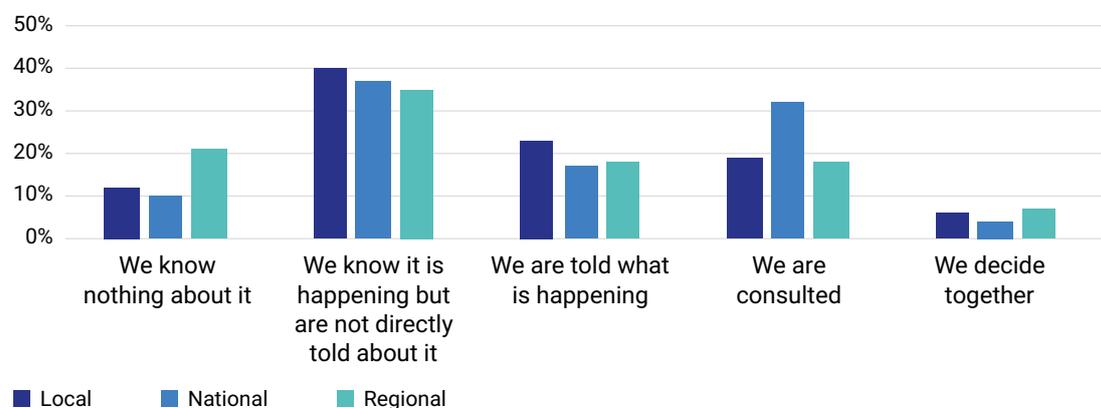
Table c2 – Level of information/ participation of OPDs in implementation of government programmes and policies

| IMPLEMENTATION	LOCAL	NATIONAL	REGIONAL
We know nothing about it	12%	10%	21%
We know it is happening but are not directly told about it	40%	38%	36%
We are told what is happening	23%	17%	18%
We are consulted	19%	32%	18%
We decide together	6%	4%	7%

Data collection

Figure d1 – OPD invitation to take part in data collection
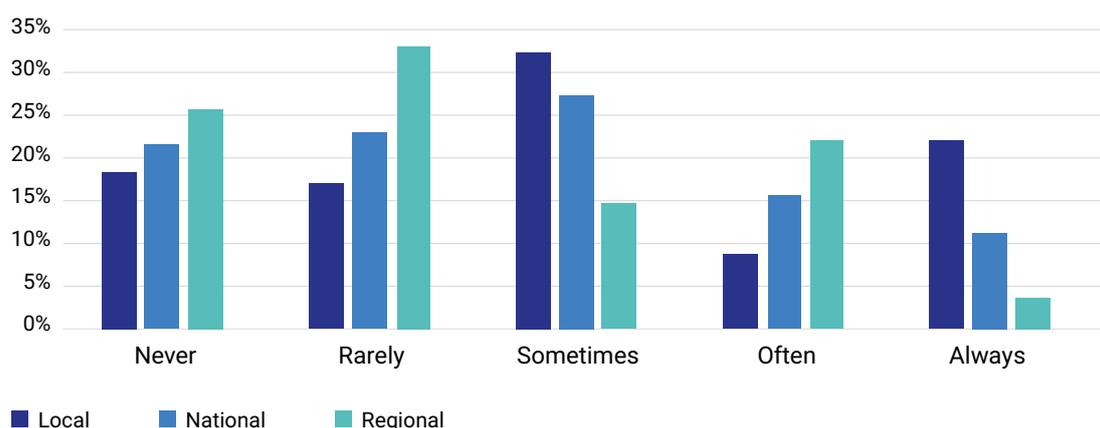
Table d1 – OPD invitation to take part in data collection

| DATA	LOCAL	NATIONAL	REGIONAL
Never	19%	22%	26%
Rarely	17%	23%	33%
Sometimes	33%	28%	15%
Often	9%	16%	22%
Always	22%	11%	4%

Figure d2 – Level of information/ participation of OPDs in data collection
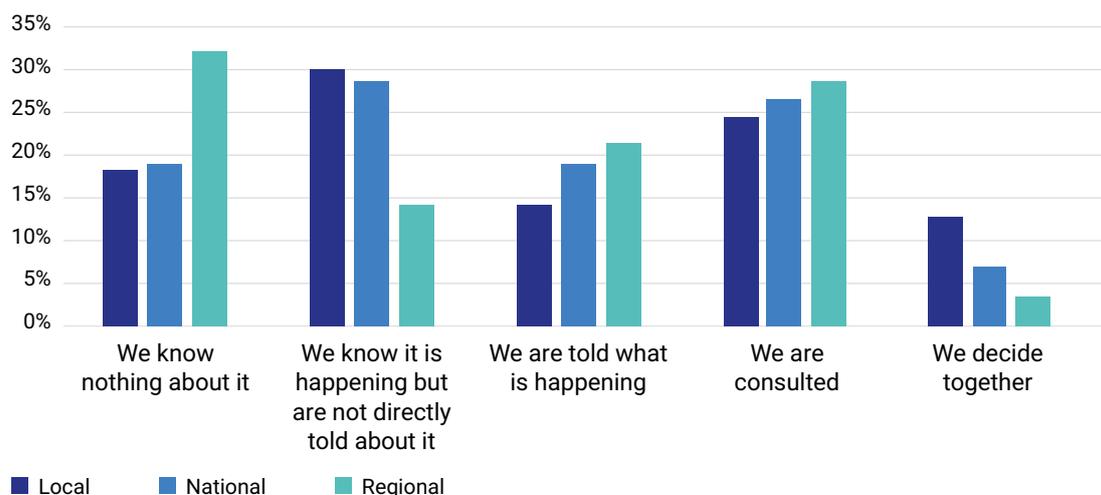
Table d2 – Level of information/ participation of OPDs in data collection

DATA COLLECTION	LOCAL	NATIONAL	REGIONAL
We know nothing about it.	18%	19%	32%
We know it is happening but are not directly told about it.	30%	29%	14%
We are told what is happening	14%	19%	21%
We are consulted	25%	27%	29%
We decide together	13%	7%	4%

Monitoring

**Figure e1 – OPD invitation to take part in monitoring of government policies and programmes**
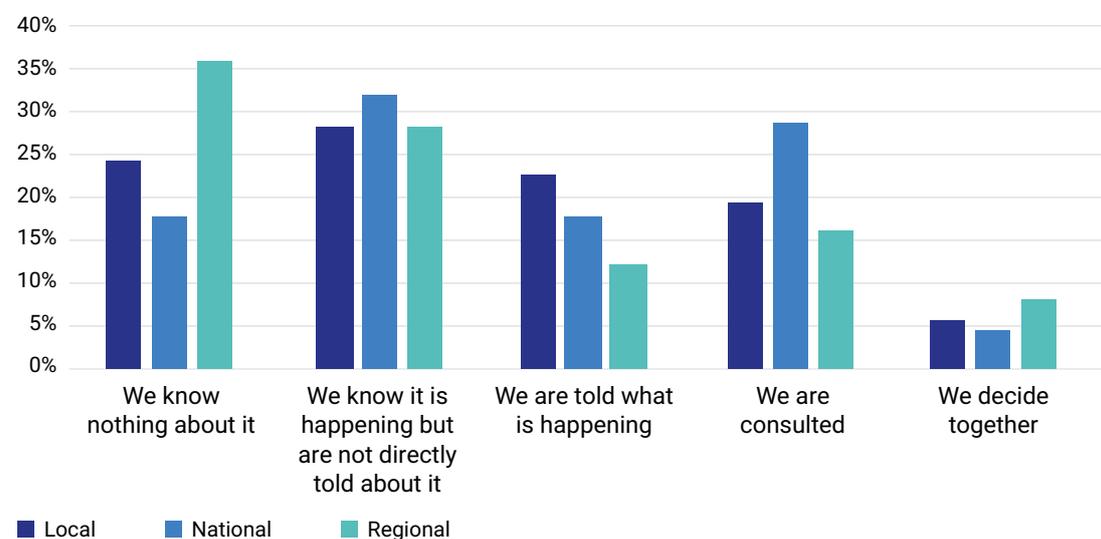
Table e1 – OPD invitation to take part in monitoring of government policies and programmes

MONITORING	LOCAL	NATIONAL	REGIONAL
Never	29%	22%	25%
Rarely	26%	24%	25%
Sometimes	26%	25%	29%
Often	8%	19%	14%
Always	13%	9%	7%

Figure e2 – Level of information/ participation of OPDs in monitoring of government policies and programmes
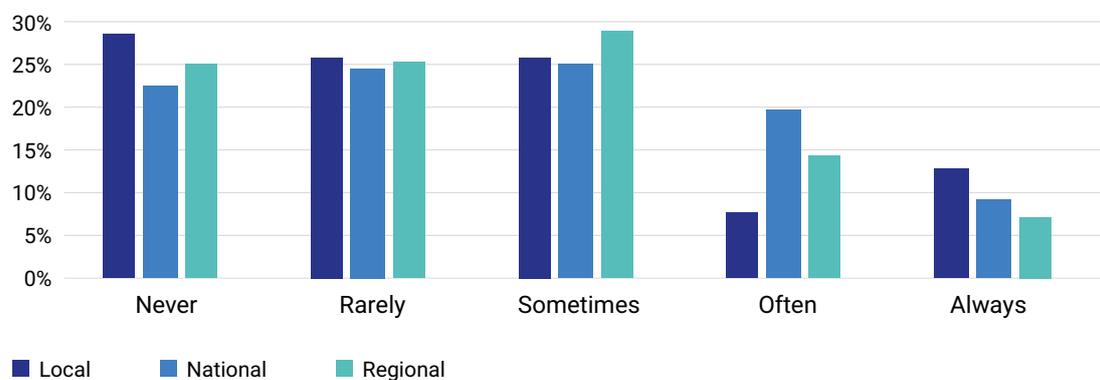

Table e2 – Level of information/ participation of OPDs in monitoring of government policies and programmes

MONITORING	LOCAL	NATIONAL	REGIONAL
We know nothing about it	24%	18%	36%
We know it is happening but are not directly told about it	28%	32%	28%
We are told what is happening	23%	18%	12%
We are consulted	19%	28%	16%
We decide together	6%	4%	8%

Annex 5

Learning and considerations for future surveys

Technological options for online surveys

Beyond survey outcomes, the Global Survey generated immense learning on the technological feasibility of a wide-scale, multilingual and accessible online survey, reaching out to a wide audience in the disability rights movement.

While accessibility was a primary concern, the software had technical limitations, which significantly impacted the survey implementation and, in some cases, also the dataset. These included, among others, challenges in management of multiple languages[57], the lack of video upload options, limitations regarding skip options within the survey section, along with formatting issues impacting the user-friendliness of the survey[58], and the stability of surveymonkey platform for our purpose[59].

From this experience, IDA is now building on this experience to develop a more accessible online survey solution, including decentralised access management, support for a wider range of users and ownership of the survey at different levels. This will greatly help us to enhance the accessibility and strengthen the scientific validity of future surveys.

Potential for further analyses and complementary research

The impact of the IDA Global Survey as a process has been very positive, as per the external evaluation of the Disability Catalyst Programme (DFID, Finland), which funded the survey[60].

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57 Concerns for quality of the translated questionnaires resulted in the decision to not use automated translations, which required 7 different surveys later on translated back in English, collated and reconciled into a single dataset.

58 This included for example the lack of an option to display definitions of complex terms as a bubble only when hovering the mouse over the word; definitions were added below the text of each question, which made the display quite 'heavy'.

59 Notably when downloading the dataset, leading to discrepancies in how responses were displayed across different languages.

60 Buettgen, A., Hardie, S., Crawford, C., Mounier, E., & Grisim, K. (2020). Independent Evaluation of IDA's Disability Catalyst Programme: Realising the rights of persons with disabilities through the SDGs. Canadian Centre on Disability Studies Incorporated operating as Eviance. "Several key informants described the IDA Global Survey as "one of the greatest tools" for gathering evidence on the extent of participation and inclusion of people with disability in development programmes and policies".

Based on the good representation secured for this baseline, IDA and IDA members will keep reflecting on ways to decentralize the hosting of the survey, or envisage the implications of a survey focused on OPD members but not limiting one response per OPD. This may allow for a wider range of responses and increased possibilities for data disaggregation.

The contribution of civil society to inclusive development implies both the capacity of CSOs to articulate the demands of marginalised groups and a certain level of willingness and ability of authorities to develop related policy responses[61]. Participation is a two-way relationship involving OPDs and decision-makers in a given context. While the IDA Global Survey intentionally focused on OPDs' perceptions, further analyses of the types of context (e.g. using the Civicus categorization of political environments) would be helpful to better characterize different types of contexts within which OPDs operate. While participation is a right and an obligation for authorities, its realisation obviously depends on the governance context and political economy.

The high standards set by the CRPD for OPD participation build on the requirement of transparent and open democratic functioning. Some comments from respondents clearly indicate that sometimes participation is used to legitimize a process and preserve a status quo. How are these relationship and opportunities influenced in more constrained political contexts? How does international cooperation investment (with government and/or with OPDs) influence outcomes? What are the determinants and conditions for meaningful participation?

These may be important elements for future IDA Global Surveys to encompass to provide a better understanding of the relationship between OPDs and decision-makers. In a context of shrinking civic space, this may also be helpful to understand strategies to enhance space for participation, and for addressing power dynamics. Such an analysis may further guide strategic investments in enhancing OPDs' capacities to challenge the status quo and effectively engage to make societies more inclusive.
It could also be interesting to explore further how participation is impacted, positively or negatively, by changed working practices in adaptation to the unprecedented global Covid-19 pandemic.

In the next iteration of the survey IDA will seeks to define dimensions of meaningful participation, through developing an OPD Participation Index, as a synthesis and monitoring tool.

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61   Cote, A. and al (2020). [The unsteady path towards meaningful participation of persons with disabilities](). Bridging the Gap Project.

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