



Participation of Organisations of Persons with Disabilities in Development Programmes and Policies

IDA Global Survey
Initial report
2019



Ministry for Foreign
Affairs of Finland

Executive Summary

Participation of persons with disabilities: ‘Nothing about us without us’ is a legal obligation

Participation of citizens is a fundamental principle of democratic societies. It supports good governance and social accountability¹, by allowing people to exert control over decisions that affect their lives. Persons with disabilities being excluded from decision-making processes perpetuates their exclusion from all areas of society, as their perspectives are systematically ignored, leading to public policies and programmes that are not responsive, not effective and continue to hinder their rights.

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.

Recent years have shown a clear momentum towards the inclusion of persons with disabilities through new global commitments, and question is no longer whether to include but how to include persons with disabilities. In this moment, it is of crucial importance that these commitments are transformed into concrete actions that are completely underpinned by the CRPD. Inclusive development requires respect for the active role of organisations of persons with disabilities as key stakeholders to reflect the views of the diversity of persons with disabilities, and orient efforts in compliance with human rights obligations.

IDA Global Survey: an accountability tool to monitor DPO involvement

With this Global Survey, IDA wants to take stock of the participation of organisations of persons with disabilities in programmes and policies, by assessing their own perceptions of the quality, depth, scope and relevance of their participation. The IDA Global Survey aims to first establish a baseline and become a regular tool to measure progress against it, through reiterating the survey every two years.

IDA’s intention is that the Global Survey can be the first ever DPO-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 includes learning for 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.

¹ A/HRC/31/62, para. 13.

Scope, methodology and accessibility

The questionnaire covered a wide range of a dimensions of participation, for example the types of stakeholders with whom DPO participate, the issues on which they are invited to participate, groups that are consulted, mechanisms and stages of the policy/ programme cycle at which they can take part, barriers and facilitators to participation, evolution and satisfaction of DPOs with their participation, etc.

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 (one response per organisation). The questionnaire was developed and tested with a group of respondents who also commented on its accessibility.

The final Global Survey questionnaire was developed in English plain language disseminated online in Arabic, Chinese, English, French, Russian, Spanish and International Sign. It was launched on the 3rd of December 2018. 573 DPOs responded to the questionnaire, covering 165 countries.

Preliminary findings

This initial report presents preliminary findings of the first IDA Global Survey on DPO participation in development programmes and policies.

It provides a unique, wide-scale 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). This brings new evidence confirming empirical observations that IDA could make so far, including that DPOs are:

- Overall DPOs reported being more engaged with their governments than with the UN and funding agencies, and among the latter, more engaged with disability-focused agencies
- Overall DPOs reported being more engaged in disability-specific issues and socio-economic issues than with issues relating to civil and political rights
- Some constituencies of persons with disabilities (persons with visual, physical and hearing impairments) are more involved than others (the most marginalised/underrepresented groups)
- Overall while DPOs reported feeling that their involvement and influence had increased as compared to one year ago, the majority remain dissatisfied with the level of engagement with government.

Next steps

Further analyses will be conducted to produce a consolidated report at a later stage, including associations between different questions and disaggregation by region or level of DPO work (from local to global). The consolidated report will also go deeper in the review of responses to open-ended questions, to confirm the provisional analyses presented in this initial report. It will also address questions related to frequency of DPO participation with governments, UN and funding agencies, stages of the policy or programme cycle in which they are most involved, or other determinants of participation such as preconditions in terms of accessibility of venues, information, appropriate attitudes, etc.

Key findings will be translated into the 7 survey languages and plain language so as to ensure feedback to respondents. IDA will also explore further options to develop decentralised ways of administering the survey, interactive visualisation tools, the development of a DPO participation index, and other routes to develop ownership of the Global Survey by organisations of persons with disabilities.

Acknowledgements

The analysis of the data collected through the first IDA Global Survey was done in partnership with the Assistive Living and Learning (ALL) Institute, Maynooth University, Ireland.

IDA is particularly thankful to Dr. Joanne McVeigh, Prof. Malcolm MacLachlan, Dr. Delia Ferri and Dr. Hasheem Mannan for their technical assistance in the production of this report. IDA also wishes to thank Alexandre Cote from the Centre for Inclusive Policies, and Ailis Hardy from Inclusion International, for their valuable contributions.

IDA also wishes to extend their gratitude to the Ministry of Foreign Affairs, Finland and the Department for International Development of the United Kingdom for their financial support to this work.

Background and rationale: Participation of persons with disabilities through their representative organisations

From rights to obligations

Participation is a human right, which is often denied to persons with disabilities

Participation of citizens is a fundamental principle of democratic societies. It supports good governance and social accountability², by allowing people to 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 treaties³. A human rights-based approach to public decision-making requires the active and informed participation of everyone in decisions that affect their lives⁴.

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 the capacity to meaningfully contribute in any way beneficial to their community and societies.

Persons with disabilities being excluded from decision-making processes perpetuates their exclusion from all areas of society, as their perspectives are systematically ignored, leading 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

These entrenched discriminations affecting all areas of life called for an urgent recognition and reaffirmation of the human rights of all persons with disabilities, and the disability rights movement took a very active part in negotiating and drafting the Convention on the Rights of Persons with Disabilities (CRPD). As the result of the force, 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. Participation is a general principle (Article 3), which cuts across all of the CRPD, and a general obligation (Article 4.3). Participation in society on an equal basis with others as an outcome requires participation as a

² A/HRC/31/62, para. 13.

³ 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

⁴ Office of the United Nations High Commissioner for Human Rights, Principles and Guidelines for a Human Rights Approach to Poverty Reduction Strategies, para. 64.

process, 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 measures⁵. 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.

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”⁶.

Article 4.3: ‘Nothing about us without us’ becomes a legal obligation

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 control⁷. It all stresses the importance of ensuring that the wide diversity of persons with disabilities are represented in consultations.

The General Comment 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 restriction⁸. 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.

CRPD, Article 4 – General obligations

States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities

⁵ CRPD/C/GC/7, para. 18, page 5

⁶ Löve L, Traustadóttir R, Quinn G, Rice J. The inclusion of the lived experience of disability in policymaking. *Laws* 2017; **6** (33): 1-16, p.3

⁷ CRPD/C/GC/7, para. 15, 17, page 5

⁸ CRPD/C/GC/7, para. 28, page 7

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.

The role of organisations of persons with disabilities

The CRPD stresses the importance of organisations of persons with disabilities as representative organisations. Organisations of persons with disabilities play a critical role in supporting participation of persons with disabilities in public life. They act as intermediary bodies to represent and convey the perspective of their constituencies. Organisations of persons with disabilities are only those that are led, directed and governed by persons with disabilities⁹, and bring a unique perspective to speak on their own behalf.

Towards stronger commitments

New commitments to include persons with disabilities from governments, the UN and funding agencies

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 CRPD¹⁰.

At the global level, through intense advocacy efforts of the disability rights movement, prominent commitments have been secured over the past four years. These include notably the inclusion of explicit references to persons with disabilities in the 2030 Agenda for Sustainable Development and global indicator framework, with clear commitments from governments to leave no one behind.

The United Nations have undertaken a review of the UN system's current approach to accessibility and mainstreaming the rights of persons with disabilities across its operations. This served as a basis to guide the development of a policy, action plan and accountability framework. The UN System Wide Action Plan (SWAP) now renamed UN Disability Inclusive Strategy (UNDIS) opens doors for significant reforms and progress by the UN at all levels.

At the level of funding agencies, the Global Action on Disability (GLAD) network has been created as a venue for bilateral, multilateral donor agencies, private sector and foundations to

⁹ CRPD/C/GC/7, para. 11, page 4

¹⁰ CRPD/C/GC/7 para 7, page 2

exchange and make strategic use of their leverage power in order to accelerate the realisation of the CRPD in development and humanitarian action contexts. This enabled for example to secure the adoption of an OECD/ DAC disability marker on disability, and to incentivize a common approach to SDG data disaggregation by disability.

In 2018, the first ever Global Disability Summit organised by the Government of the United Kingdom and co-hosted by the Government of Kenya and the International Disability Alliance, also led to a set of 170 commitments from a range of world leaders, some of them engaging on disability-inclusive development for the first time. Overall, the discourse successfully shifted from *whether* to include persons with disabilities to *how* to include. Over the past four years, IDA has experienced positive developments with regards to the number, diversity and scope of requests for contributions from organisations of persons with disabilities.

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

At the same time, the CRPD Committee in 2018 also 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 programmes¹¹. Similarly, IDA through its members has empirical evidence that organisations of persons with disabilities are not yet invited, nor seriously considered as trusted interlocutors or development partners.

While global level developments in terms of recognition of disability rights are very positive, the implications of a human-rights based approach to disability and public decision-making are not yet understood, enacted nor monitored. Participation of organisations of persons with disabilities is not systematised or not yet in meaningful ways, even in programmes that claim to advance disability rights. Most marginalised groups of persons with disabilities, such as persons with deafblindness, persons with intellectual disabilities, persons with psychosocial disabilities, are often not consulted at all.

Risks that commitments are not backed by a human rights-based approach

IDA sees significant risks for the advancement of the rights of persons with disabilities if global commitments made on inclusion of persons with disabilities are not backed by a real transformation of practices and meaningful consultation of their representative organisations. Indeed, enhanced attention to disability 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 the rights of persons with psychosocial disabilities through a health entry point and medical approach that contradicts a right-based model, the provisions of the CRPD and may diminish the rights to be included in the community. 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 etc.

¹¹ CRPD/C/GC/7 para 8, page 2

Towards stronger accountability

The IDA Global Survey: evidence for accountability

In this context, it is important that the disability rights movement plays an active role in engaging with governments to guide legal, policy and services reforms, and continuously strengthens its capacity to engage and ascertain its views in decision-making processes. Meanwhile, it is also important that the reality of engagement, consultation, involvement and participation in programmes and policies is analysed.

With this Global Survey, IDA wants to take stock of the participation of organisations of persons with disabilities in programmes and policies, by assessing their own perceptions of the quality, depth, scope and relevance of their participation. The IDA Global Survey aims to first establish a baseline and become a regular tool to measure progress against it, through reiterating the survey every two years. IDA's intention is that the Global Survey can be the first ever DPO-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 includes learning for 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.

The IDA Global Survey on Participation of Organisations of Persons with Disabilities in Development Programmes and Policies

Scope of the IDA Global 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 captured 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 (DPO) is any organisations or association that is governed by people 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.

Participation

The IDA Global Survey entails questions that enable to analyse different dimensions of participation. These include:

- **Type of stakeholders with whom DPOs participate (Where? With whom?):** Which stakeholders engage with organisations of persons with disabilities? At which level(s)?
- **Areas of participation (On what?):** On which topics are organisations of persons with disabilities invited to participate?
- **Diversity of groups invited to participate (Who?):** Which groups of persons with disabilities are consulted?
- **Types of mechanisms and conditions for participation (When? How?):** How regular and formalised are mechanisms that enable participation of organisations of persons with disabilities? At which steps of the policy/ programme cycle do organisations of persons with disabilities participate? Are the preconditions established for meaningful participation?
- **Extent and quality of participation outcomes (For what?):** Are organisations of persons with disabilities involved in the most influential stages such as governance or budgeting? How influential is the participation of organisations of persons with disabilities? How is participation evolving over time? How satisfied are organisations of persons with disabilities with their participation?

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. 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 the questionnaire.

The consultation found that about 60% of respondents (8 out of 13) indicated they were aware of the UNPRPD, of which 100% (13) said DPOs have been involved/ consulted in some way in the UNPRPD project. However, some groups were perceived by DPOs as less involved than others¹², and satisfaction with their engagement was contrasted¹³.

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

¹² 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.

¹³ This fast-track consultation provides a contrasted picture of DPOs' 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).

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 website¹⁴, 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 questionnaire comprised a total of 120 items; and was categorised into four main sections:

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

The full questionnaire is available in [Annex 1](#).

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

¹⁴ www.internationaldisabilityalliance.org/global-survey

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.

Data analysis

Two research assistants conducted preliminary cleaning of the data. The questionnaire was vetted¹⁵ 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 IDA Global Survey brings an interesting dataset for potential 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.

Accessibility of the IDA Global Survey

Language

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. It is worth noting that translators and people 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.

Managing multiple languages was time-consuming, including the challenges of collating the multiple datasets into one single dataset in English. This impacted the range of possible analyses that could be completed before the release of the present initial report.

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

¹⁵ Ravitch SM, Mittenfelner Carl N. Qualitative research: Bridging the conceptual, theoretical, and methodological. Thousand Oaks, CA: Sage; 2016.

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.

While accessibility was broadly ensured, the software had technical limitations, which significantly impacted accessibility and/or dataset clearing stage. This included, among others:

- Limitation of multiple language survey functions, which required 7 different surveys later on collated into a single dataset
- No option to upload video responses
- Limitation of question skip options within a survey section
- Limited formatting options, including 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'
- Lack of stability when downloading the dataset, leading to discrepancies in how responses were displayed across different languages.

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). However, we have no evidence of whether or not this was done by some of the respondents.

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 (see following section).

The development of such a wide-scope survey in accessible format was a pioneer experience in many ways 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.

The Initial Global Survey report

As of March 2019, IDA and the ALL Institute at Maynooth University completed a first level of analyses of the descriptors for each survey question, which are reflected in this initial report. Due to technical difficulties generated by the software, cleaning the final English dataset required more time than initially anticipated. However, this was an indispensable step to ensure reliability of the data, and subsequent analyses.

Further analyses will be conducted to produce a consolidated report at a later stage, including associations between different questions and disaggregation by region or level of DPO work (from local to global). The consolidated report will also go deeper in the review of responses to open-ended questions, to confirm the provisional analyses presented in this initial report. It will also address questions related to frequency of DPO participation with governments, UN and funding agencies, stages of the policy or programme cycle in which they are most involved, or other determinants of participation such as preconditions in terms of accessibility of venues, information, appropriate attitudes, etc.

Key findings will be translated into the 7 survey languages and plain language so as to ensure feedback to respondents. IDA will also explore further options to develop decentralised ways of administering the survey, interactive visualisation tools, the development of a DPO participation index, and other routes to develop ownership of the Global Survey by organisations of persons with disabilities.

Analysis of respondents to the IDA Global Survey

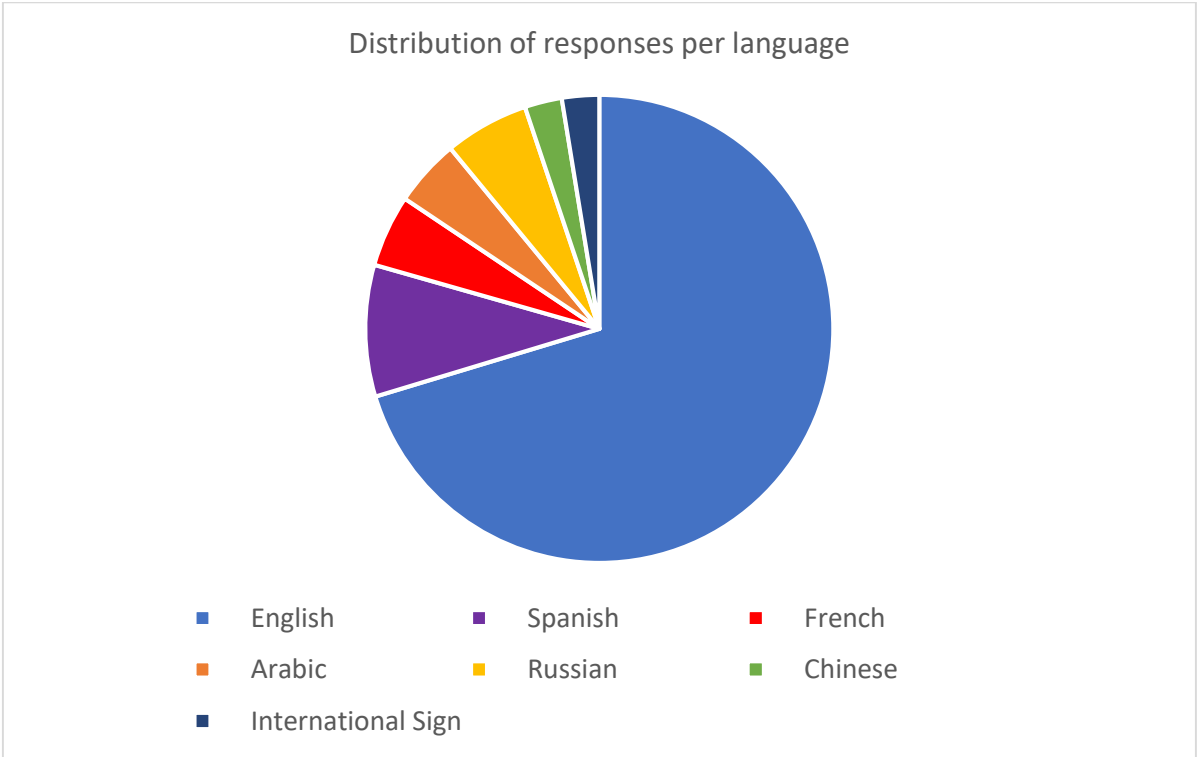
Individual respondents' population

The questionnaire had a total of **573 respondents** (with one response per organisation of person with disabilities). The questionnaire included 6 opening questions which only aimed at characterizing the population of respondents (and assess the outreach of the survey including potential accessibility issues). As responses were collected per organisation of persons with disabilities, this information is not used further in the report to disaggregate data by identity factor of respondents.

Language

Distribution of responses per language (Chart 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

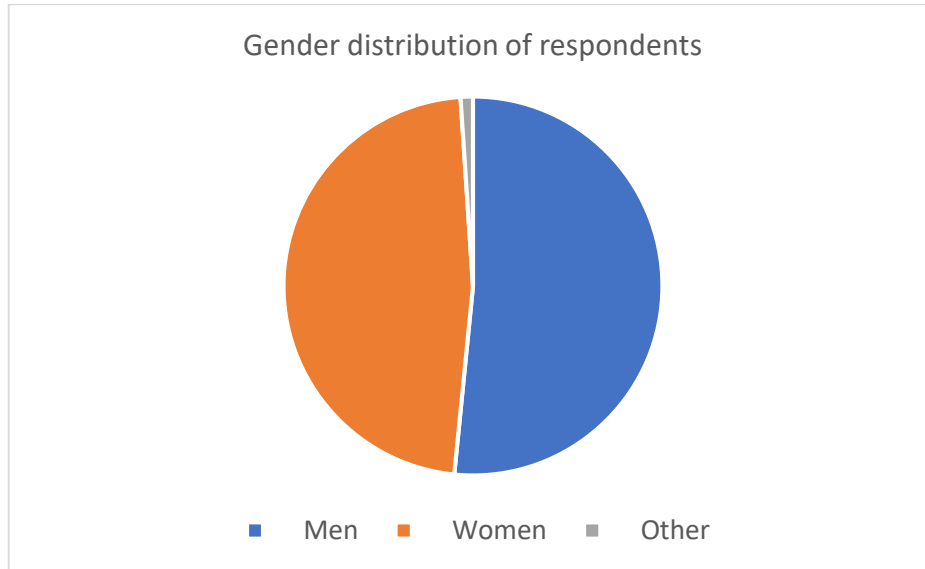


Age and gender

The average age of respondents was 45 (SD = 13.4), which suggests that respondents are relatively experienced. This average is relatively high as compared to the average age of populations from low- and middle-income countries where the majority of persons with disabilities live.

Distribution of gender (Figure 2) showed 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 gender



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 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.

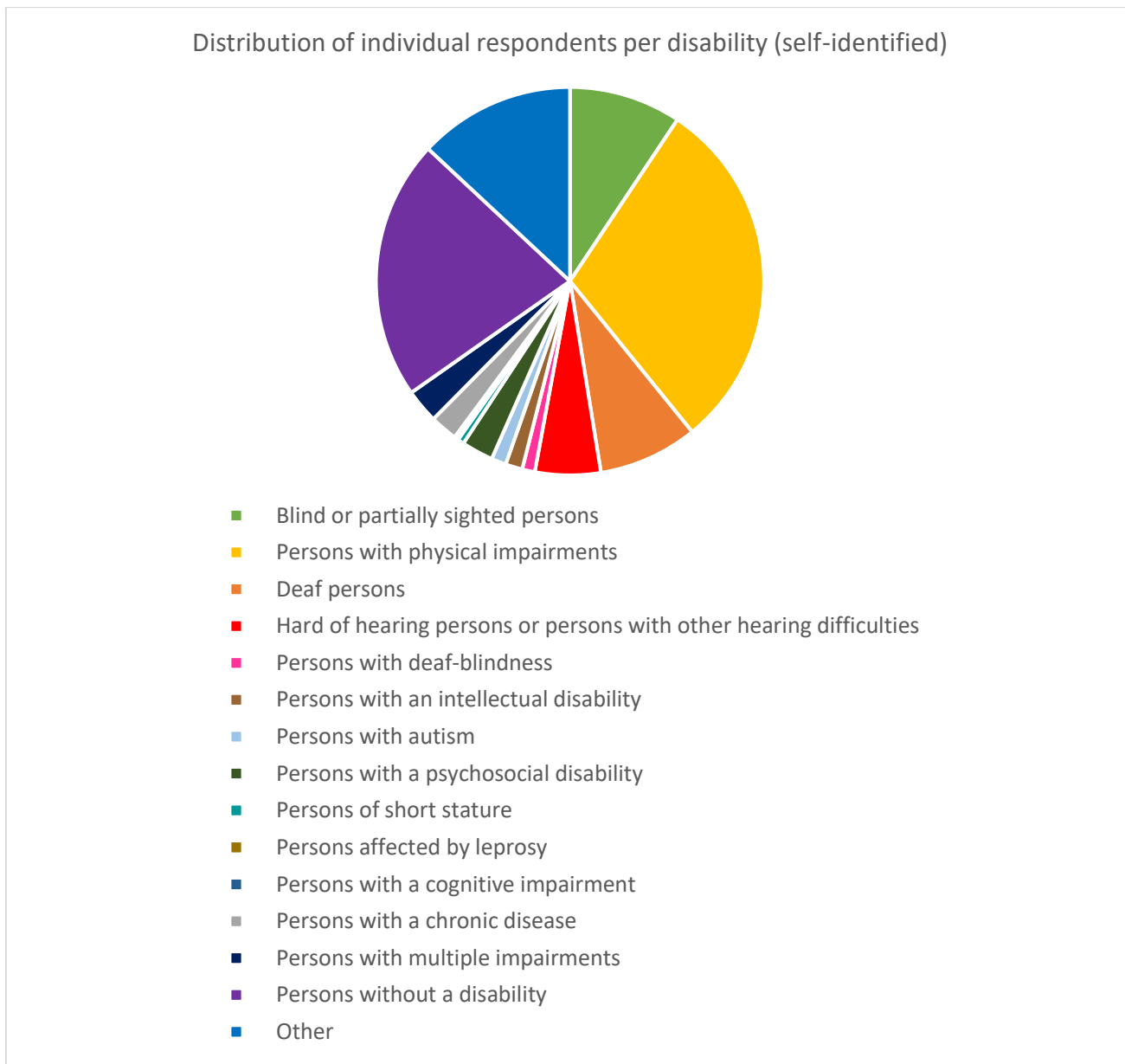
Distribution as shown in Figure 3 and Table 1 below reflects a higher proportion of respondents with physical impairments (29.8%), followed by persons without a disability (21.7%), while the lowest number of responses are from persons who self-identified as persons affected by leprosy or persons with a cognitive impairment (0.2% each).

Table 1 – Distribution of respondents per disability (self-identified)

Disability constituencies	Number of Participants	%
<i>Blind or partially sighted persons</i>	53	9,3%
<i>Persons with physical impairments</i>	169	29,8%
<i>Deaf persons</i>	47	8,3%
<i>Hard of hearing persons or persons with other hearing difficulties</i>	31	5,5%
<i>Persons with deaf-blindness</i>	6	1,1%
<i>Persons with an intellectual disability</i>	8	1,4%
<i>Persons with autism</i>	7	1,2%
<i>Persons with a psychosocial disability</i>	15	2,6%

Persons of short stature	3	0,5%
Persons affected by leprosy	1	0,2%
Persons with a cognitive impairment	1	0,2%
Persons with a chronic disease	13	2,3%
Persons with multiple impairments	16	2,8%
Persons without a disability	123	21,7%
Other	74	13,1%

Figure 3 – Distribution of individual respondents per disability (self-identified)



Other information on individual respondents

Support to complete the survey: A total of 94 (16.5%) respondents reported receiving support from another person to complete the questionnaire.

Bridge CRPD-SDGs training alumni: 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

Table 2 provides countries in which respondents' DPOs worked. DPOs 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 = 47¹⁶) in the Pacific; the United States (n = 11) in North America; and Colombia (n = 10) in South America.

Table 2 – Countries in which DPO respondents work¹⁷

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

¹⁶ The relatively high response rate for New Zealand (given its relatively small size) may be due to a much higher degree of networking and/or international awareness among DPOs, resulting in a more comprehensive response.

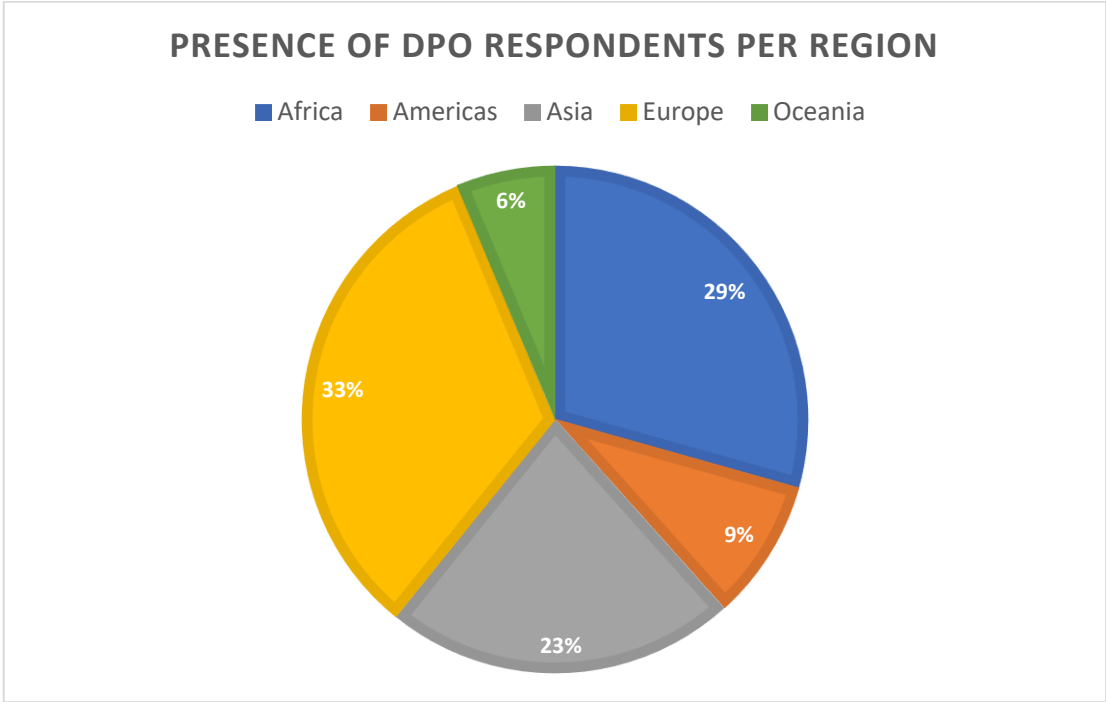
¹⁷ The cumulated number of countries does not reflect the number of responses to the survey, but the number of countries in which DPO respondents work. Global and regional organisations of persons with disabilities selected multiple countries yet responded only once to the survey.

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

A grouping of the above countries per region¹⁸ indicates that DPO respondents to the survey work in the following regions (see Figures 4 below): 315 responses from organisations of persons with disabilities working in Europe, 281 in Africa, 215 in Asia, 86 in the Americas and 60 in Oceania.

¹⁸ Grouping followed five regions used by the UN: <https://unstats.un.org/unsd/methodology/m49/>

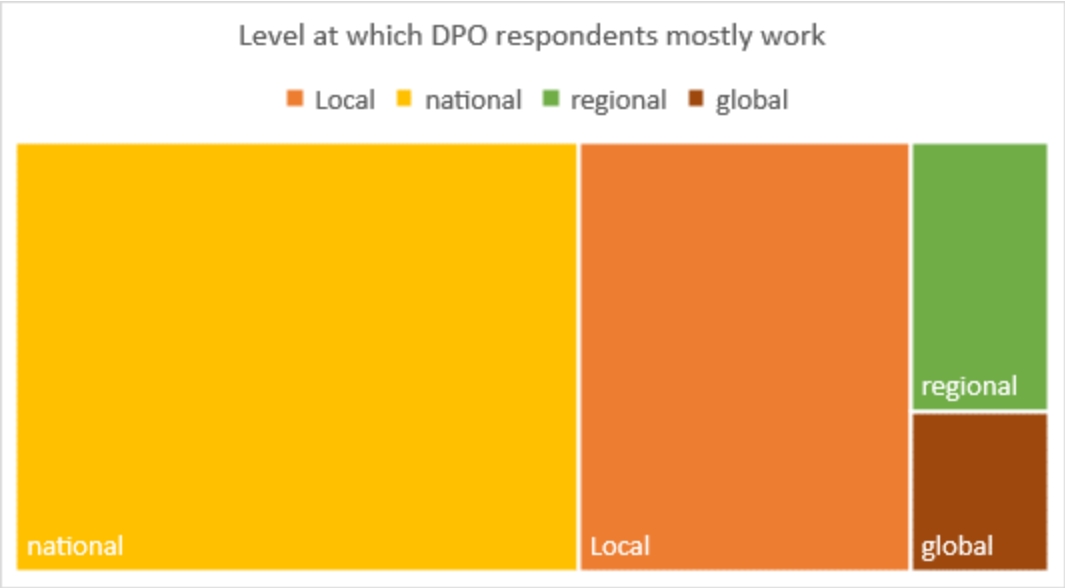
Figure 4 – Regions in which DPO respondents work



Level at which responding organisations of persons with disabilities work

A majority of DPO respondents reported that they primarily work at the national level. 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 5Error! Reference source not found. schematically presents this data.

Figure 5 - Level at which DPO respondents mostly work



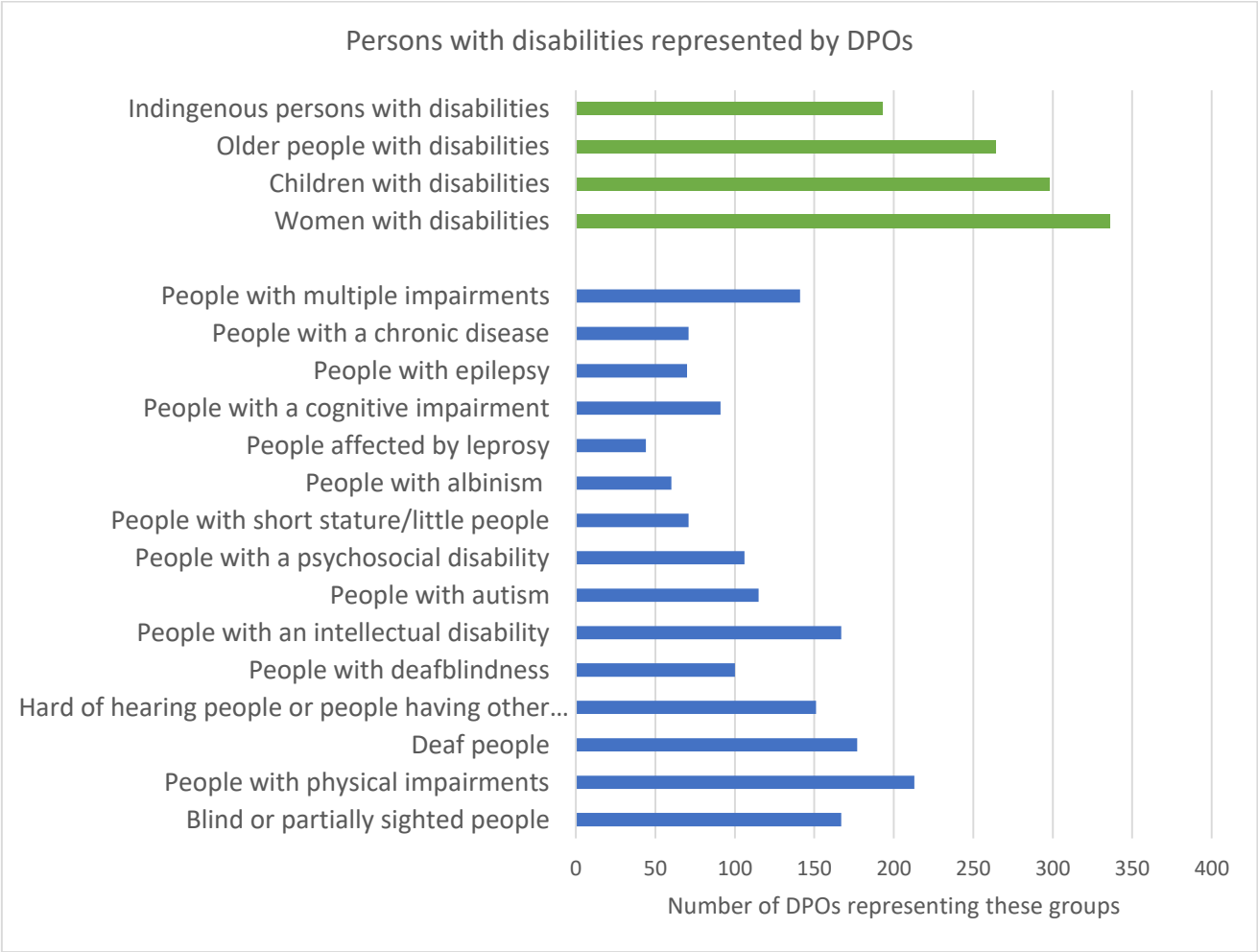
Groups represented by responding organisations of persons with disabilities

Table 3 and Figure 6 below represent the distribution of constituencies represented by responding organisations persons with disabilities.

Table 3 - Groups of Persons with Disabilities represented by DPO respondents:

Per type of impairment group:	Number of responses	% of total respondents
<i>Blind or partially sighted people</i>	167	29,1%
<i>People with physical impairments</i>	213	37,2%
<i>Deaf people</i>	177	30,9%
<i>Hard of hearing people or people having other hearing difficulties</i>	151	26,4%
<i>People with deafblindness</i>	100	17,5%
<i>People with intellectual disabilities</i>	167	29,1%
<i>People with autism</i>	115	20,1%
<i>People with psychosocial disabilities</i>	106	18,5%
<i>People with short stature/little people</i>	71	12,4%
<i>People with albinism</i>	60	10,5%
<i>People affected by leprosy</i>	44	7,7%
<i>People with a cognitive impairment</i>	91	15,9%
<i>People with epilepsy</i>	70	12,2%
<i>People with a chronic disease</i>	71	12,4%
<i>People with multiple impairments</i>	141	24,6%
Per intersection with other identity factor:		
<i>Women with disabilities</i>	336	58,6%
<i>Children with disabilities</i>	298	52,0%
<i>Older people with disabilities</i>	264	46,1%
<i>Indigenous persons with disabilities</i>	193	33,7%

Figure 6 – Persons with disabilities represented by DPO respondents (in blue: per type of impairment group; in green: per intersection with other identity factor)



Survey outcomes: Participation of organisations of persons with disabilities with their governments, the United Nations and funding agencies

With whom?

Participation of DPOs by type of decision-maker

This section shows that overall, respondents indicate higher levels of involvement with governments than with UN agencies or funding agencies, which can be explained by government’s primary role as a duty-bearer for the implementation of the UNCRPD.

Among UN agencies, respondents are more involved with UNDP, UNICEF, WHO and OHCHR, and identify UNICEF and UNDP as the most inclusive of persons with disabilities. Among funding agencies, respondents do not distinguish clearly between the types of donors but report higher rates of involvement with International non-governmental organizations (INGOs) focused on disability and government funding agencies. This indicates that disability is still mostly an issue covered by specific agencies and yet to be embraced by a larger pool of donors.

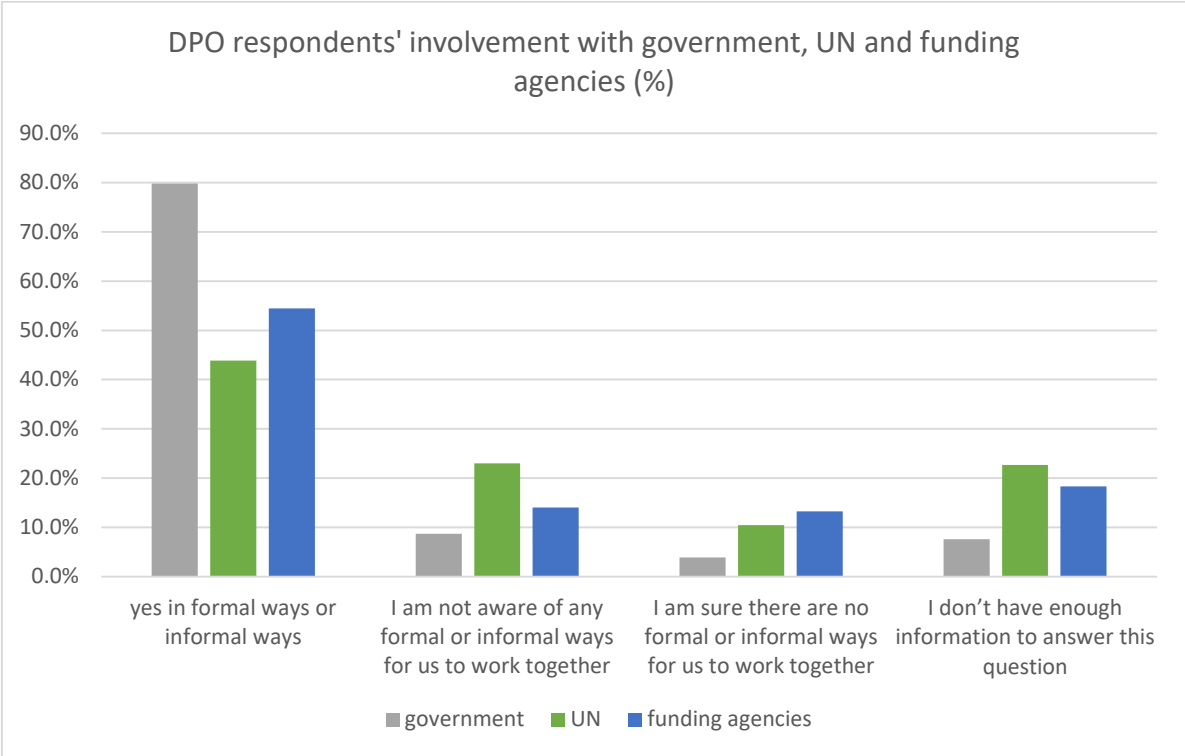
Level of involvements with governments, UN and funding agencies

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 UNCRPD. Further disaggregation of the results by level at which DPOs primarily work will identify if there are differences (for example: are regional DPOs comparatively more involved with the UN). This is illustrated in Table 4 and Figure 7 below.

Table 4 – Nature of 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)

	Government Nb (%)	UN Nb (%)	Funding agencies Nb (%)
Involvement of DPO respondents			
<i>Yes in formal ways or informal ways</i>	367 (79,8%)	122 (43,9%)	140 (54,5%)
<i>I am not aware of any formal or informal ways for us to work together</i>	40 (8,7%)	64 (23,0%)	36 (14,0%)
<i>I am sure there are no formal or informal ways for us to work together</i>	18 (3,9%)	29 (10,4%)	34 (13,2%)
<i>I don’t have enough information to answer this question</i>	35 (7,6%)	63 (22,7%)	47 (18,3%)

Figure 7 – Respondents’ involvement with governments, UN and funding agencies



Involvement of organisations with persons with disabilities with UN agencies

Organisations of persons with disabilities reported being involved with UN agencies as described in Table 6 below. A large percentage of respondents (23.2%) indicate that they are not sure with agency or programme of the UN they are involved¹⁹. UNDP, UNICEF, WHO and OHCHR appear on the top of the list. It is interesting to note that there is 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 (a programme of the UN active in 39 countries as of the time during which the Survey was open for response).

Table 6 – UN Agencies cited as involving DPO respondents

UN Agency:	number	%
UNDP	50	8,7%
UNICEF	45	7,9%
WHO	42	7,3%
OHCHR	41	7,3%
UNPRPD	36	6,3%
UN Women	31	5,4%
ILO	26	4,5%
OCHA	7	1,2%
I am not sure	133	23,2%

¹⁹ 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.

Agencies reported as the most inclusive are reported in Table 7. UNICEF and UNDP are clearly singled out by respondents as the most inclusive agencies.

Table 7 – UN agencies considered the most inclusive by DPOs

UN Agencies:	Number
UNICEF	21
UNDP	19
UN Women	8
WHO	8
ILO	7
OHCHR	7
ESCAP	2
Committee on the Rights of Persons with Disabilities	2
UNFPA	2
UNESCO	2

Involvement of organisations with persons with disabilities with funding agencies

A relatively large percentage of respondents (18.7%) indicated they were ‘not sure’ of the type of funding agencies that they are involved with. **Error! Reference source not found.**Others indicated that they are involved primarily with the following categories:

1. International non-governmental organizations (INGOs) focused on disability (12.6%)
2. Government funding agencies (9.6%)
3. Foundations (9.6%)
4. International non-governmental organizations (INGOs) not focused on disability (5.1%)
5. Humanitarian actors (3.1%)
6. Development banks (1.4%)

Respondents singled out the Disability Rights Fund (DRF) and CBM (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.

Several comments in response to related open-ended questions suggest that respondents have limited knowledge of funding agencies (e.g. ‘Don't have much knowledge on funding agencies in our part of country’) or that they understood participation and consultation by funding agencies mostly as the possibility to access funding (‘Many donors have either stopped or reduce funding mainly due to finance barriers are facing in their funding base thus affecting DPOs by and large’ or ‘The funds provided as grant is very small’). This would need to be further explored in the consolidated report.

On what?

Issues on which DPOs are invited to participate

This section shows that DPO respondents report being involved mostly on disability-specific issues, but also on a wide range of socio-economic issues (education, health, employment and social protection), followed by civil and political issues (such as gender equality, access to justice, participation in political life, protection against violence).

Issues on which organisations of persons with disabilities 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, the appointment of the administrative authorities governing disability-specific policies or public policies in the field of education, health, work and employment²⁰. 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 they are also consulted in a wide range of areas not specific to disability. 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 DPOs 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. Table 6 and Figure 9 below provide the detailed quantitative results.

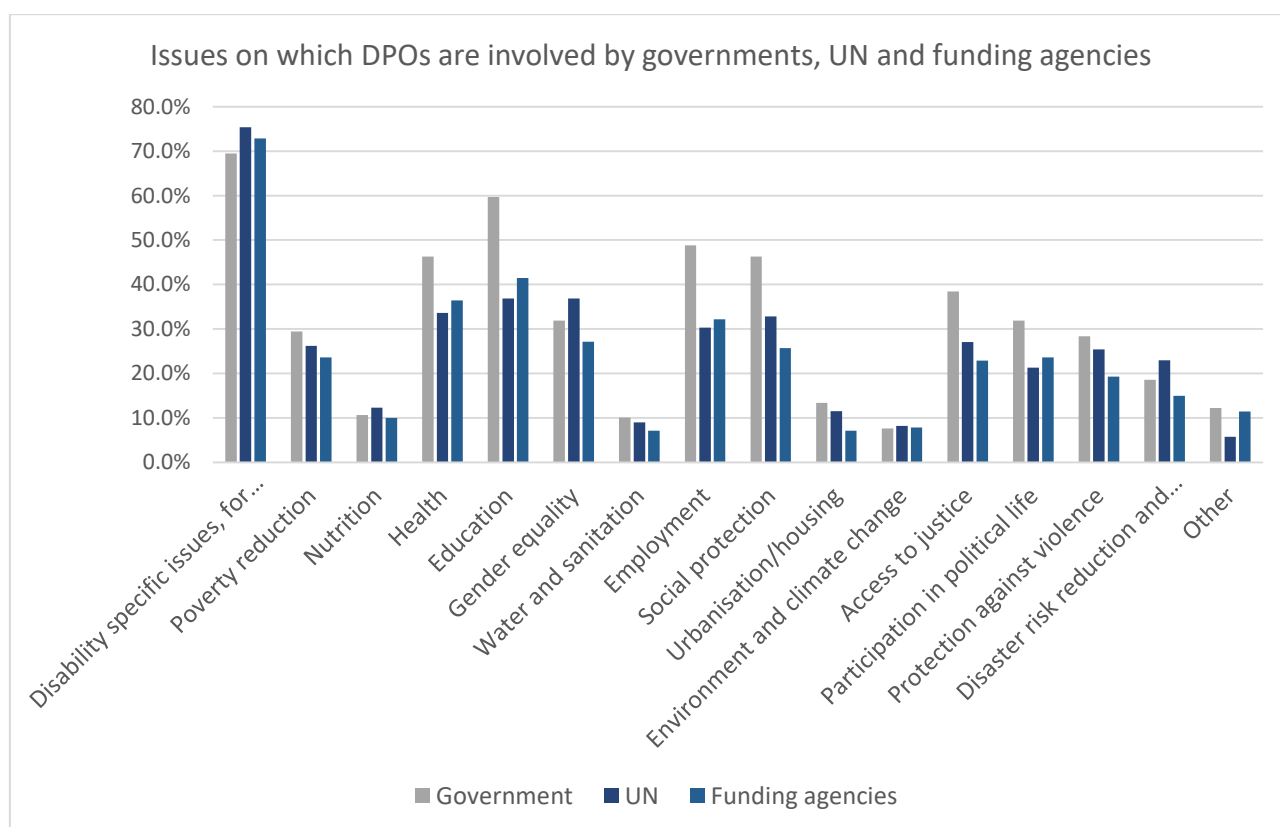
Table 8 – Issues on which DPOs are involved by governments, UN and funding agencies (% as indicated by respondents who indicated being involved with these stakeholders)

	Government	UN	Funding agencies
<i>Disability specific issues, for example working on laws on disability</i>	69,5%	75,4%	72,9%
<i>Poverty reduction</i>	29,4%	26,2%	23,6%
<i>Nutrition</i>	10,6%	12,3%	10,0%
<i>Health</i>	46,3%	33,6%	36,4%

²⁰ CRPD/C/GC/7 para 20.

Education	59,7%	36,9%	41,4%
Gender equality	31,9%	36,9%	27,1%
Water and sanitation	10,1%	9,0%	7,1%
Employment	48,8%	30,3%	32,1%
Social protection	46,3%	32,8%	25,7%
Urbanisation/housing	13,4%	11,5%	7,1%
Environment and climate change	7,6%	8,2%	7,9%
Access to justice	38,4%	27,0%	22,9%
Participation in political life	31,9%	21,3%	23,6%
Protection against violence	28,3%	25,4%	19,3%
Disaster risk reduction and humanitarian action	18,5%	23,0%	15,0%
Other	12,3%	5,7%	11,4%
Don't know	3,8%	3,3%	5,7%

Figure 9 – Issues on which DPOs are involved by governments, UN and funding agencies (% as indicated by respondents who indicated being involved with these stakeholders)



Who?

Participation of the diversity of persons with disabilities

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 diversity²¹, 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.

Distribution of disability constituencies involved with government, UN and funding agencies

Table 5 and Figure 8 below compare consultation of different constituencies of persons with disabilities respectively by governments, the UN and funding agencies. This only captures responses from DPO respondents who indicated above that their organisation is involved (in formal or informal ways) with these stakeholders – filtered as having direct experience of engagement.

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.

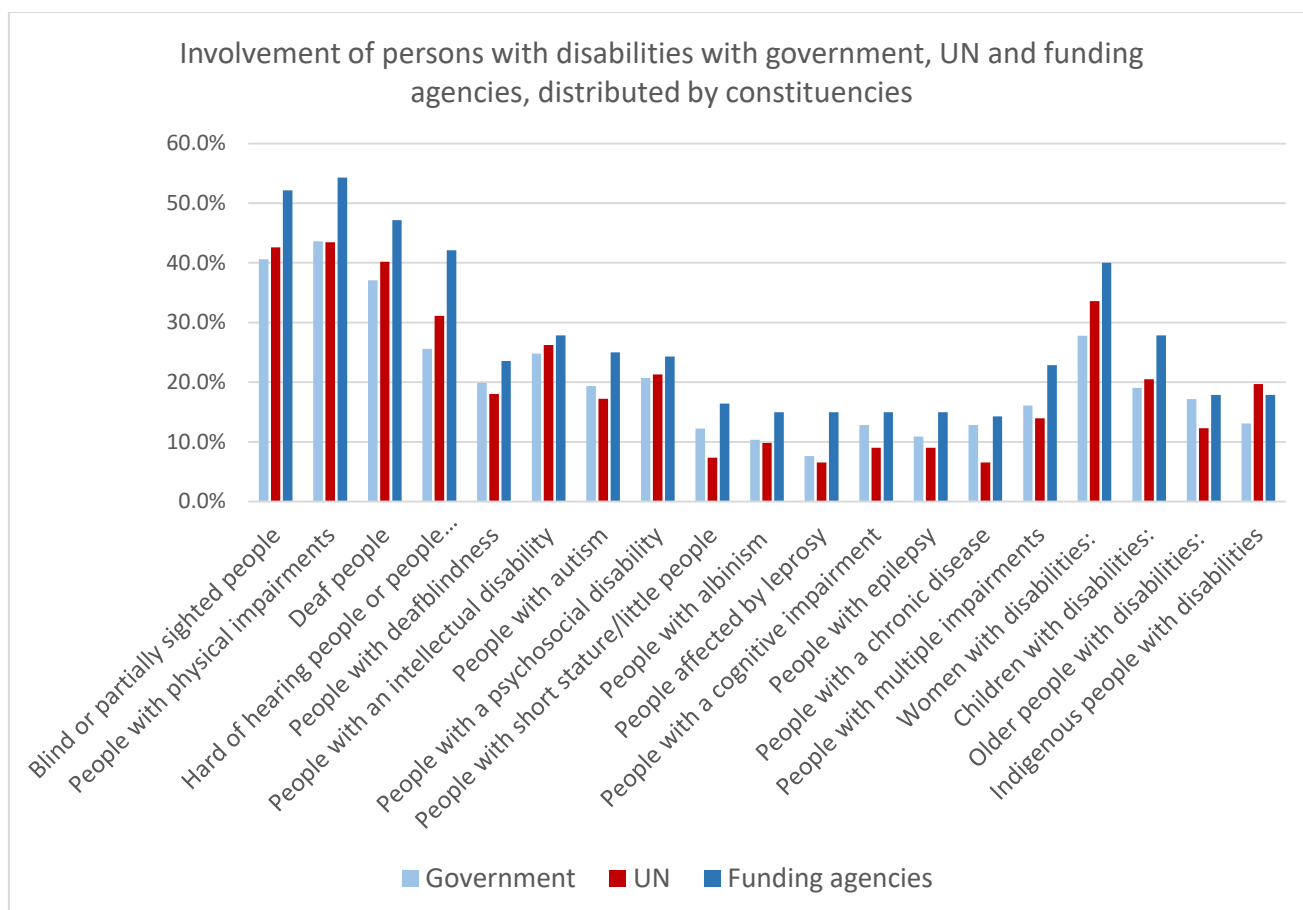
Table 5 – *Involvement of different constituencies of persons with disabilities by government, UN and funding agencies as perceived by DPO respondents engaged with these stakeholders*

Per type of impairment group:	Government	UN	Funding agencies
<i>Blind or partially sighted people</i>	40,6%	42,6%	52,1%
<i>People with physical impairments</i>	43,6%	43,4%	54,3%
<i>Deaf people</i>	37,1%	40,2%	47,1%
<i>Hard of hearing people or people having other hearing difficulties</i>	25,6%	31,1%	42,1%
<i>People with deafblindness</i>	19,9%	18,0%	23,6%
<i>People with an intellectual disability</i>	24,8%	26,2%	27,9%
<i>People with autism</i>	19,3%	17,2%	25,0%
<i>People with a psychosocial disability</i>	20,7%	21,3%	24,3%
<i>People with short stature/little people</i>	12,3%	7,4%	16,4%
<i>People with albinism</i>	10,4%	9,8%	15,0%
<i>People affected by leprosy</i>	7,6%	6,6%	15,0%
<i>People with a cognitive impairment</i>	12,8%	9,0%	15,0%
<i>People with epilepsy</i>	10,9%	9,0%	15,0%
<i>People with a chronic disease</i>	12,8%	6,6%	14,3%

²¹ CRPD/C/GC/7, in particular para. 15, 27, 40, 76, 90, 94.g

People with multiple impairments	16,1%	13,9%	22,9%
Per intersection with other identity factor:			
Women with disabilities:	27,8%	33,6%	40,0%
Children with disabilities:	19,1%	20,5%	27,9%
Older people with disabilities:	17,2%	12,3%	17,9%
Indigenous people with disabilities	13,1%	19,7%	17,9%

Figure 8 – Involvement of persons with disabilities by governments, UN and funding agencies, distributed by constituency



Discrepancies in participation across constituencies of the disability movement

“Many groups are not included and are very marginalised, especially women with disabilities, blind people, deafblind, persons with intellectual or psychosocial needs, the elderly with disabilities, independent watchdog groups and individual activists ... it is important to include their voices and for the government, international organisations, donors, and mainstream civil society to hear their voices and give them due credibility”

(IDA Global Survey respondent)

Further analyses will be conducted in a consolidated version of the report to disaggregate responses provided by DPOs on their participation according to the types of constituencies that they represent.

Meanwhile, preliminary analysis of the information provided in open-ended questions suggests that **some groups are less represented than others in consultations with government, UN and funding agencies**. Persons with visual impairments, physical impairments and hearing impairments are considered to have more access than persons with intellectual disabilities, persons with deafblindness or indigenous persons with disabilities.

For example: *‘Usually not involved but only powerful lobby of activists mainly featuring the physical disabilities of locomotor and visual impairment sometimes make their way’* or *‘Government only consult with some of groups of Blind, Deaf and Physical disabilities and some parents’ groups’*. Other comments flag the absence of consultations of some groups: *‘Indigenous, Madhesis and Dalit groups are not consulted in any discussion of events, programs and policies’*; *‘People with disabilities who are homeless and displaced people with disabilities (inclusive of refugees and asylum-seekers) are not involved. People with autism and intellectual disabilities are involved through proxy, not directly’*.

For what?

Evolution, efficiency and satisfaction of DPOs with their participation

This section shows that as compared to one year ago, respondents perceive that their involvement is improving, which suggests that the global momentum on inclusion of persons with disabilities is somewhat impacting levels of participation of representative organisations. Their involvement and influence appear as strongly correlated according to respondents.

Respondents are overall more pleased than displeased with their involvement with funding agencies. However, despite positive trends, there are significantly more respondents that are displeased than pleased with their involvement with their government.

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

Table 9 and Figure 10 below presents responses for change compared with one year ago regarding the perception by DPO respondents of their level of *involvement* and of their level of *influence* DPOs with government or regional organisations, the UN, and funding agencies²².

There are similarities in evolutions of DPO involvement and of DPO 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 DPOs perceive that when they are involved, they do have influence**. Examples provided in response to a question on an impact that would not have happened without DPOs are largely examples of DPO influence on

²² 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”.

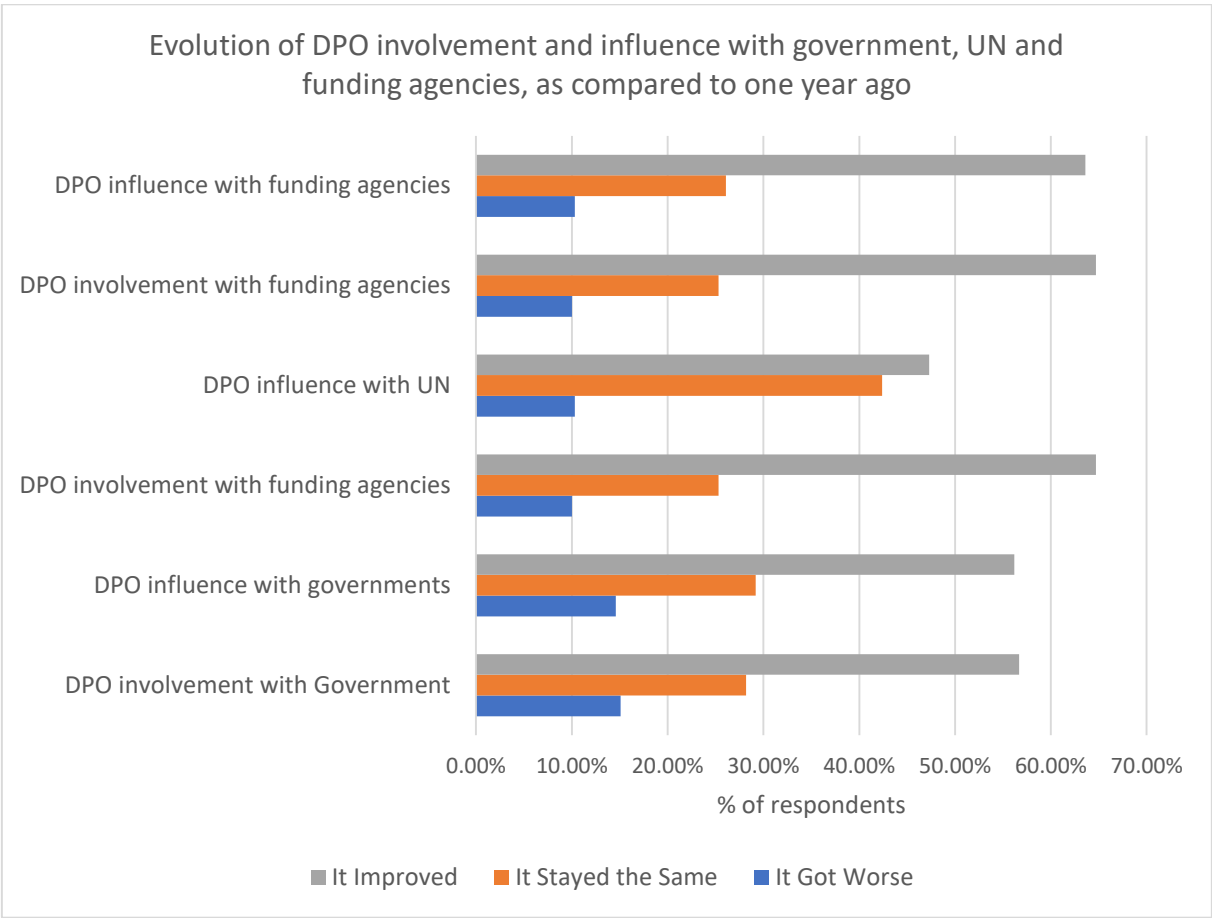
policy review/ reform, accessibility, social protection, awareness of the rights of persons with disabilities and access to elections.

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.

Table 9- Evolution of DPO involvement and influence with government, UN and funding agencies, as compared to one year ago (nb of respondents)

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 Got Worse	15,10%	14,60%	10%	10,30%	10%	10,30%
It Stayed the Same	28,20%	29,20%	25,30%	42,40%	25,30%	26,10%
It Improved	56,70%	56,20%	64,70%	47,30%	64,70%	63,60%

Figure 10- Evolution of DPO involvement and influence with government, UN and funding agencies, as compared to one year ago (% of respondents)



Overall satisfaction of DPOs with their engagement

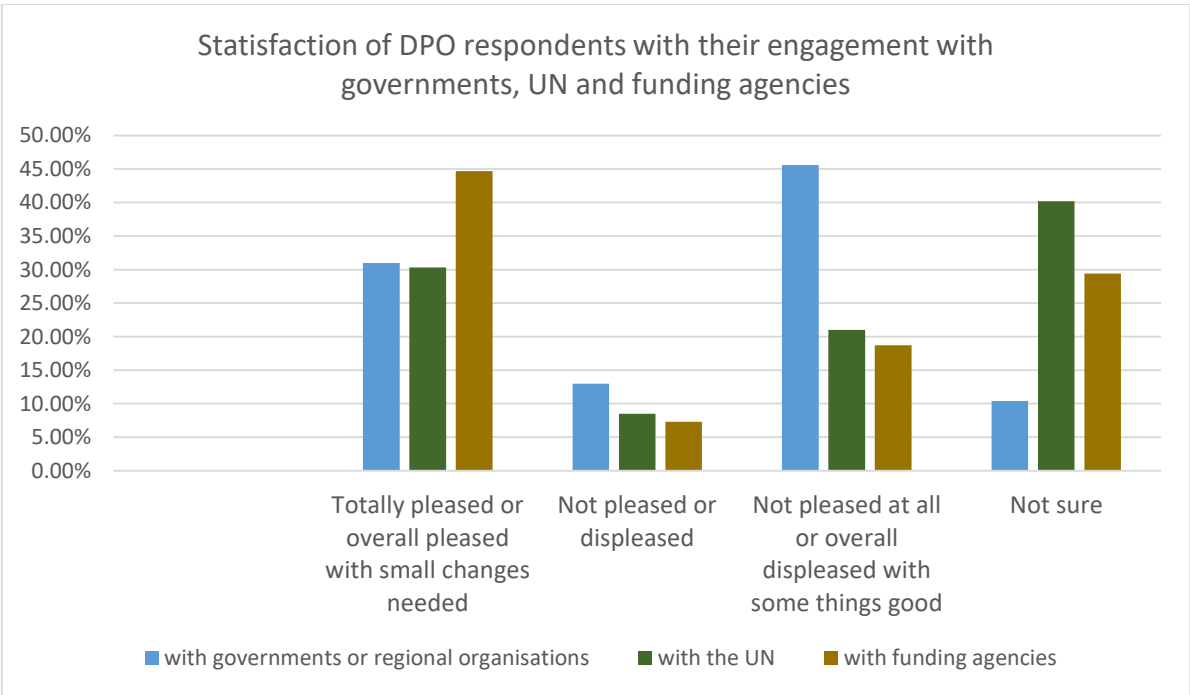
Table 10 and Figure 11 present responses for the three items “Overall, as a DPO, how pleased are you with the work you have done with your government or regional organisation?”, “Overall, as a DPO, how pleased are you with your work with the UN?”, and “Overall as a DPO, how pleased are you with your work with funding agencies?”.

Results show that DPOs 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%).

Table 10 – Satisfaction of DPO 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 government (%)	with the UN (%)	with funding agencies (%)
Totally pleased or overall pleased with small changes needed	31,00%	30,30%	44,70%
Not pleased or displeased	13%	8,50%	7,30%
Not pleased at all or overall displeased with some things good	45,60%	21,00%	18,70%
Not sure	10,40%	40,20%	29,40%

Figure 11 – Satisfaction of DPO respondents with their engagement with government, UN and funding agencies (% of respondents)



Preliminary conclusions and next steps

This report presents preliminary findings of the first IDA Global Survey on DPO participation in development programmes and policies.

It provides a **unique, wide-scale 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). This brings new evidence confirming empirical observations that IDA could make so far, including that DPOs are:

- Overall DPOs reported being more engaged with their governments than with the UN and funding agencies, and among the latter, more engaged with disability-focused agencies
- Overall DPOs reported being more engaged in disability-specific issues and socio-economic issues than with issues relating to civil and political rights
- Some constituencies of persons with disabilities (persons with visual, physical and hearing impairments) are more involved than others
- Overall while DPOs reported feeling that their involvement and influence had increased, the majority remain dissatisfied with the level of engagement with government.

Most interesting analyses are yet to be conducted to **provide a more comprehensive baseline** against which change can be measured. It is anticipated that the consolidated report will include:

- Confirmation of the provisional conclusions of the initial report, backed by further associations and text analysis of responses to open-ended questions
- Analysis of complementary questions relating to preconditions for participation, stages of policy and programme cycle, frequency of participation
- Analysis of responses per constituencies represented by DPO respondents
- Analysis of responses per region
- Analysis of responses per primary level of work of DPO respondents (local DPOs, national, regional or global)
- Associations and correlations relevant to IDA, its members and partners.

Beyond survey outcomes, the Global Survey generated immense learning on the technical feasibility of a wide-scale, multilingual and accessible online survey reaching out to a wide audience in the disability rights movement. IDA also wants to build on this experience to reflect on opportunities of a decentralised, movement-owned **consultation instrument to support monitoring of participation** at different levels.