



**UNPRPD** **FUND**

Partnership on the Rights of Persons with Disabilities

# **Guidance note on effective and meaningful participation of persons with disabilities through their representative organizations in UNPRPD Joint programing**

**2024**

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# I. Introduction

Organizations of persons with disabilities (OPDs) play an important role within civil society to defend the rights of persons with disabilities, advocate for changes in policies, practices and social norms, monitor government actions, and provide information and solutions for alternative policies and systems. In addition to being fundamental to the vibrancy of civil society, persons with disabilities and their representative organizations play an essential role in holding governments to account for the implementation of the Convention on the Rights of Persons with Disabilities (CRPD). They are also essential partners to governments, donors, human rights institutions, development stakeholders and actors working on emergency response and climate change action.

Participation of OPDs is not only good practice, but also a fundamental human right. As stated in the Convention on the Rights of Persons with Disabilities (CRPD) in Article 4 (3) General Obligations, governments should closely consult with persons with disabilities, including children with disabilities, through their representative organizations on the implementation of legislation and policies and other decision-making processes relevant to their lives. Participation of OPDs in the implementation and monitoring of the CRPD is an obligation of States Parties and these obligations are clarified by the CRPD Committee in its General Comment 7.<sup>1</sup> Meaningful participation also ensures good governance and accountability and aligns with the disability movement's motto, 'nothing about us without us.'

Engagement of persons with disabilities also leads to stronger outcomes in the long term. OPDs have unique technical expertise to understand the changes that are needed to enable full participation on an equal basis. This is an untapped resource in many contexts and there is a needed shift by governments to move from viewing OPDs as recipients of aid and services to implementing partners.

## II. The aim of the guidance note

The Guidance Note outlines UNPRPD Fund's commitment to partnership with representative organizations of persons with disabilities in programming and provides practical advice to UN Country Teams (UNCTs) applying to UNPRPD Fund as well as Participating UN organization (PUNOs) implementing UNPRPD Fund programs on meaningful engagement with persons with disabilities and their representative organizations. The annexes included in the guidance provide practical guidance on how to identify and outreach to OPDs, understanding the diversity and structure of the disability movement, examples of effective engagement in UNPRPD programs and learning on OPD participation in UNPRPD programs.

UNPRPD Fund Technical Secretariat developed this guidance to:

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<sup>1</sup> CRPD, General Comment no. 7: on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention, twentieth session, adopted Sept 2018, CRPD/C/GC/7

1. Support participating UN organisations (PUNOs) to effectively engage OPDs in programming from the inception phase to program implementation and monitoring processes.
2. Address common challenges and gaps in fostering meaningful participation.
3. Support PUNOs to move from basic consultation with OPDs to genuine partnership with strategies for more effective engagement and outreach to and inclusion of a diversity of persons with disabilities.
4. Support PUNOs in understanding the disability movement in the national context, developing genuine partnerships for change, adopting accessible and inclusive practices for engagement and designing and delivering relevant capacity building for OPDs to engage.
5. Provide insight into how to develop spaces and mechanisms for joint decision-making and priority setting.

### III. What is meaningful participation of OPDs

While there is no commonly acknowledged definition of meaningful participation of OPDs, the International Disability Alliance has attempted to define it as, “Meaningful participation that respects, values and considers the unique role and perspective of OPDs as organizations 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.”<sup>2</sup>

**For UNPRPD Fund, persons with disabilities, through their representative organisations, must be equal partners in UNPRPD Fund programs and have decision-making roles in policy and systems changes that affect them.** Their perspectives and expertise must be included in policy and systems changes needed to accelerate CRPD implementation and advance the rights of all persons with disabilities. They must also be provided with capacity building to be able to engage in policy and systems changes with UN agencies, government and other stakeholders on an equal basis.

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<sup>2</sup> International Disability Alliance, “Promoting Engagement of Organizations of Persons with Disabilities in Development and Humanitarian Action, Global Disability Summit Discussion (GSD) Paper, 2022,” (NORAD), page 13: Global Disability Summit (GDS) Discussion Paper, 2022 ([internationaldisabilityalliance.org](http://internationaldisabilityalliance.org)).

## IV. What are OPDs and understanding the diversity of the disability movement

### What is an OPD

OPDs are non-governmental, representative organizations or groups of persons with disabilities, where persons with disabilities constitute a majority of the overall members, staff, board, and volunteers, at all levels of the organization. OPDs may be cross-disability meaning they represent different disability groups (e.g., persons with physical disabilities, persons with psychosocial disabilities, Deaf persons etc.) or they may represent one distinct constituency (e.g., deafblind persons or women with disabilities). OPDs, like the disability community, are diverse. They can be organized as formal membership-based structures, peer-support groups, collectives, self-advocacy groups or more loose and less formal groups.<sup>3</sup> They may work locally, nationally, regionally, or internationally. OPDs raise awareness, advocate on disability rights, support their constituencies / members, and in some cases may deliver services or support service delivery by others. Parents, family members and relatives can also form OPDs representing persons with intellectual disabilities, children with disabilities and older persons with disabilities with dementia, when these groups want to be supported by these groups.<sup>4</sup> They can act as spokespersons and supporters. For more information on the diversity of the disability movement and how the movement is organized see [Annex VI](#).

Groups led solely by persons with intellectual disabilities are most commonly called self-advocacy groups. Self-advocacy groups can be part of a of a Parent Association or a separate organisation. These groups have been marginalized within civil society, but more and more self-advocates are organizing themselves and becoming politically active on rights and inclusion issues.<sup>5</sup> Smaller and less formal OPDs may not have legal status or national accreditation in a given country. These conditions should not preclude PUNOs from engaging and consulting with these organizations. For more information about how to identify OPDs see [Annex I](#).

OPDs are different from organizations “for” persons with disabilities that provide services or advocate on their behalf. Service providers delivering services to persons with disabilities are not OPDs. For example, organizations providing mental health support are not organizations representing persons with psychosocial disabilities. Service providers providing resources and support to persons with intellectual disabilities such as resource centres or day centres are not organizations representing persons with intellectual disabilities. Some OPDs do provide services as part of the overall mandate.

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<sup>3</sup> UNDIS - [un\\_disability-inclusive\\_consultation\\_guidelines.pdf](#)

<sup>4</sup> UN Disability Inclusion Strategy Guidelines for Consulting with Persons with Disabilities, page 8, available at: [un\\_disability-inclusive\\_consultation\\_guidelines.pdf](#)

<sup>5</sup> Inclusion International and Down Syndrome International are two global organizations that have self-advocacy led members in various countries around the world. They have resources and tools to support organizations in outreaching to and effectively engaging with organizations led by persons with intellectual disabilities.

Persons with disabilities are uniquely qualified to share knowledge on how best to include, reach, and respond to the requirements of persons with disabilities because of their own lived experience. Organizations who provide services to persons with disabilities or who advocate on their behalf but do not represent persons with disabilities may be knowledgeable on disability issues, but they lack the significance of lived experience of a diverse group of persons with disabilities that OPDs possess.

## Understanding the diversity of the disability movement: who is less represented and which groups are more marginalized

Like many communities, the disability community is diverse. There are many different disability groups with different needs and priorities. Some groups are less represented within the disability movement and for those who face multiple and overlapping forms of discrimination on the basis of their disability and other factors, they are even more marginalized. Underrepresented groups of persons with disabilities such as persons with intellectual disabilities, persons with psychosocial disabilities, persons with albinism, deafblind persons, little people and persons with multiple disabilities. These groups are often less represented in the disability movement.

In terms of disability and gender, in many contexts, women with disabilities are less represented in leadership positions within the disability movement. Women with disabilities have faced barriers to accessing leadership positions within the dis Persons with disabilities are uniquely qualified to share knowledge on how best to include, reach, and respond to the requirements of persons with disabilities because of their own lived experience. Organizations who provide services to persons with disabilities or who advocate on their behalf but do not represent persons with disabilities may be knowledgeable on disability issues, but they lack the significance of lived experience of a diverse group of persons with disabilities that OPDs possess. ability movement but women with disabilities are forming membership-based organizations as well as cross-disability collectives.

More work is needed to outreach to and engage marginalized persons with disabilities. UNPRPD defines marginalized persons with disabilities as those that face multiple and overlapping forms of discrimination on the basis of their disability and other factors such as age, sex, gender, gender identity or expression, sexual orientation, ethnic minority status, indigenous origin, location, economic status etc. There are efforts to develop organisations representing indigenous peoples with disabilities as well as persons with disabilities of diverse SOGIESC in some countries (see Annex VI for more explanation on how the disability movement is structured and ensuring engagement with a diversity of constituents).

### Why does diversity matter?

Diversity of persons with disabilities is important because the interventions and solutions to tackling barriers and ensuring support may differ from one group to another.

For example, children with physical disabilities are often excluded from education due to a lack of ramps, accessible toilets, access to wheelchairs or mobility devices; whereas children who are deaf are often excluded because teachers, students and others in the school do not use Sign Language or Sign Language interpretation is not available and captioning services are not provided. Both sets of students are also excluded due to an inflexible curriculum, stigma in the school and community, and teachers who are not trained in inclusive education methods. While there are some common barriers between the two groups, there are also very specific requirements of each group. Engaging with a diverse group of persons with disabilities will ensure that the requirements of all groups are met.

## How to identify OPDs

UN agencies and international development and humanitarian actors work with a variety of national and local actors who may be able to recommend OPDs that they have worked with. Many OPDs have strong relationships with government ministries, such as the ministries and departments that cover social affairs, health, education, employment, and social protection or benefits. However, there is often a department specifically devoted to disability that may be able to recommend OPDs. Other statutory bodies, such as National Human Rights Institutions and National Disability Councils, may also be able to suggest reputable OPDs. International or regional OPDs are another source for locating OPDs within each country, as many national OPDs are members of regional OPDs (see [Annex I for a list of global and regional level OPDs](#)).

It is critical to carry out due diligence when identifying and selecting OPDs to ensure the organizations being engaged are representative of their constituents' interests, practicing responsible financial and organizational management and that they are led by persons with disabilities. As part of this due diligence, it is important to ensure the OPDs being identified have not been charged with or been complicit in fraud or financial and non-financial corrupt activities etc. This helps safeguard against partnerships with fraudulent civil society organizations. UNPRPD developed a set of questions to help guide the process in [Annex I](#).

PUNOs implementing UNPRPD country programs should work with national and sub-national OPDs. There may be a handful or hundreds of OPDs nationally, depending on the size of the country, ease of registration, and history of the disability movement. Most countries have at least one national umbrella OPD, a number of cross-disability OPDs, and OPDs specifically focused on a particular group (e.g., people who are blind, women, indigenous people, etc.). There are also locally based OPDs that cover specific provinces or districts, who have specialist knowledge of their region and may also feed into national initiatives. Some groups may not have an OPD to represent them if, for example, the group experiences considerable communication barriers (such

as deafblind persons) or stigma (such as persons with HIV/AIDS) or if the OPD representing them has had funding lapses.

It is best to begin by connecting with the national umbrella OPD to connect with other OPDs. In most countries, the umbrella OPD is not sufficient for ensuring all persons with disabilities are represented, so it may be necessary to supplement with additional OPDs that focus on underrepresented groups. In countries where umbrella OPDs do not exist or where the umbrella OPD is poorly managed, national cross-disability OPDs may serve as a key partner and interlocutor. For local level engagement, umbrella OPDs with branch offices or local level OPDs are ideal partners.

## **V. Moving from consultation to participation of OPDs**

A participatory approach to the planning, design and implementation of consultations can significantly contribute to ensure consultations and engagement are meaningful. There are many ways UN entities and UNCTs can achieve this: Implementing OPD-led consultations upon formalized partnerships with UN entities and UNCTs; Co-designing and co-organizing consultations between UN entities/ UNCTs and OPDs; Consulting and engaging with OPDs throughout the planning of consultations, including on how to make them more accessible and inclusive; Collaborating with OPDs to define the objectives, agenda and desired outcomes of consultations; and/or Seeking feedback from OPDs on the consultations held, including accessibility, to improve preparation and planning of future consultations.

Meaningful participation of persons with disabilities through their representative organisations is a process as well as an outcome. In UNPRPD Fund programs, meaningful engagement should go beyond consultations to partnerships with substantive and regular collaboration in decision-making and priority setting. PUNOs should develop appropriate and transparent mechanisms for collaboration in consultation with OPDs. This will help ensure OPDs are involved meaningfully in all stages of UNPRPD program implementation cycle. Taking a participatory approach will also help ensure OPDs play more substantive roles in the design and implementation of policies, programs and systems changes to implement the CRPD. This can be done by creating formal partnerships and by involving OPDs in project advisory committees, governance committees or steering committees. It is important that partnerships and participatory mechanisms are fully accessible with clear roles and objectives aimed at joint initiatives and collective ownership. There must be transparency so that all partners can build trust with reflection about power imbalances.



## Key principles and pre-conditions for engagement

Drawing from UNPRPD Fund experience<sup>6</sup>, it is important to draw out pre-conditions for engagement. For UNPRPD Fund programs, these are the essential pre-conditions for meaningful engagement with OPDs.

- Invest in the expertise of OPDs by building in time and spaces for leveraging their knowledge
- Communication (clarity of expectations, roles, goals etc.) and information
- Transparency on the process and the mechanism for engaging/partnering
- Mutually agreed definition of roles and expectations and clear communication
- Accessibility and inclusivity of processes in which reasonable accommodations are provided and financed by PUNOs/government to create an enabling environment
- Formalized mechanisms for shared decision-making
- Trust and responsibility to work together and fulfil agreed roles
- Capacity building/empowerment of OPDs to participate in policy reform and public affairs
- Time planned for meaningful dialogue and a sincere desire to reach a collective agreement
- Respect for realistic and reasonable timelines in participatory processes
- Diversity of disability movement represented

## VI. Investment in capacity building

Meaningful participation of persons with disabilities also requires reflection around power imbalances and needed capacity building both for OPDs as well as UN and government stakeholders so that all groups understand their roles, their various capacities, strengths and weaknesses. For OPDs it is critical to have the capacity building needed to come to the table with government and UN agencies and participate in policy and law reform dialogues on an equal basis. For UN and government stakeholders, knowledge and capacity to understand disability rights issues and to provide accessible and inclusive spaces for these dialogues is also essential.

More reflection is needed around equalizing the capacity gap critique of OPDs. The framing of “limited capacity” of OPDs is misleading when persons with disabilities do not have equal access to social capital and resources as the government or other CSOs. Recognizing the power imbalances between UN entities and civil society in terms of financial resources, persons with disabilities and their representative organizations should be compensated for their time and expertise.

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<sup>6</sup> The importance of pre-conditions for engagement are also highlighted in the 2022 global survey on OPD engagement by the International Disability Alliance, OPD Engagement in Development and Humanitarian Action: Global Disability Summit (GDS) Discussion Paper, 2022: [Global Disability Summit \(GDS\) Discussion Paper, 2022 \(internationaldisabilityalliance.org\)](https://www.internationaldisabilityalliance.org/gds-discussion-paper-2022)

UNPRPD expects that at least 25% of the program budget is invested in technical and financial capacity building for OPDs. OPDs should also receive the financial support needed to participate such as covering costs for transportation to and from meetings and being provided compensation for their expertise. In addition, reasonable accommodations such as Sign Language interpretation, personal assistance and other forms of accommodations should be provided and paid for by the government, UN agencies and other stakeholders inviting OPDs to participate. These costs should not fall on persons with disabilities themselves to cover in order to participate. Examples of meaningful participation in UNPRPD Fund programs can be found in [Annex II](#).

## VII. Participation modalities in UNPRPD processes and activities

The modalities for engaging with persons with disabilities involve both the level of engagement and the circumstances of the opportunity. It is often best to formulate a long-term partnership with OPD(s) to facilitate on-going opportunities. However, ad hoc arrangements may be more appropriate in some circumstances. The modality should be **meaningful, proportionate, and appropriate to the particular opportunity**. For example, seeking input from OPDs at the final stages of program planning is often seen as insincere and meaningless. It is important to seek input from persons with disabilities on the modalities that are most appropriate for the opportunity and their capacity and priorities and to include their participation at the outset of programs, including the design phase. [Annex II](#) provides a checklist for meaningful engagement of OPDs in UNPRPD programs.

### Expression of Interest (EOI)

To apply for UNPRPD joint program funding, UNCTs must ensure that persons with disabilities are meaningfully involved in the process through their representative organizations (OPDs). This process is usually initiated with an Expression of Interest (EOI), which sets out a series of questions about the country based on the Terms of Reference (TOR) of the funding call. The EOI does not include program design elements, apart from overarching thematic priorities that are of interest to the UNCT. Therefore, most of the EOI focuses on the conditions of the country.

All UNCTs should prepare the EOI in close partnership with OPDs to ensure that UNPRPD understands the country from the perspective of persons with disabilities. If the UNCT does not have existing relationships with OPDs, then the EOI process can be used as an opportunity to initiate a working relationship going forward which can be combined with other relationship-building exercises, such as a series of meetings, webinars, or video conferences.

Possible partnership models could include:

- Establishing a **partnership agreement** with one or more OPDs to participate in the full process, which may include references to the partnership pending funding. This may then be followed up with other options below.
- Establishing a formal body, such as **feedback group or committee**, to complete the EOI either virtually or in person, which includes diverse representation of OPDs, including good gender balance and representation of underrepresented groups. It is important for the OPD representatives to be in high proportion to representatives without disabilities and to have equal status regarding decision-making. The **draft EOI should be validated** by the feedback group or committee prior to finalizing. The feedback group or committee could be used throughout the application process to discuss programming ideas, provide information and advice on the priorities of persons with disabilities, and to help shape the strategy and design of programs at later stages of the process.
- Arranging a **meeting table or discussion**, to complete the EOI with OPD representatives. It is important for the EOI to be translated into local language so OPDs can participate. Following the consultation, UNCTs should **share the draft EOI** with participating OPDs for final comments before finalizing.
- **Facilitating written feedback** on the EOI from OPDs, which includes diverse representation of OPDs, including good gender balance and representation of underrepresented groups. If there is no virtual or face-to-face meeting or event to collect information from OPDs before filling in the EOI, then UNCTs should proactively share the EOI with OPDs and ask them to fill it in and return it so that UNCTs can compile the results. Following this, the UNCT can **share the draft EOI** based on the written submissions from OPDs for final review and comments. UNCTs should avoid filling in the EOI and asking OPDs to comment after-the-fact, as this reduces the levels of participation of OPDs.
- It may be necessary to include some **capacity building** in order to complete the EOI, e.g., capacity building of UNCT staff and/or government on an overview of disability inclusion / issues concerning persons with disabilities or capacity building of OPDs on UN processes or UNPRPD programs. In either case, OPDs should be involved in these webinars, seminars, or short trainings as either facilitators, guest speakers, and/or participants. There will be opportunities for further capacity building later in the process, e.g., the Induction Workshop.
- Following the completion of the EOI, UNCTs **should keep OPDs informed** and share final versions with OPDs to ensure transparency and so OPDs know how their information was used.

In addition to completing the EOI in partnership with OPDs, UNCTs are also required to **submit a letter of endorsement from the national umbrella OPD**. If there is no umbrella OPD, then a national cross-disability OPD could provide the letter. If UNCTs have difficulty in identifying or working with OPDs or in obtaining letters of endorsement, they should contact the UNPRPD Technical Secretariat for technical support and advice.

## Induction Workshop

For shortlisted UNCTs, the Induction Workshop is a structured training developed by UNPRPD to be organized by the UNCT for all potential program partners, including UN staff, government representatives, and OPD representatives. It is an essential step in preparing national stakeholders to develop full program proposals for UNPRPD joint programs. UNPRPD provides the training materials, and the UNCT organizes the participants and identifies local facilitators, using UNPRPD allocated funds.

All UNCTs should organize and deliver the workshop in close partnership with OPDs to ensure that key program partners understand UNPRPD's strategy and how this relates to UNPRPD programs, basic information on the CRPD and disability inclusive SDGs, and introduction to the preconditions for disability inclusion. OPD representatives, including women with disabilities and underrepresented groups of persons with disabilities, must be included as participants jointly with UN staff and government representatives, as these three groups should take precedence over other types of partners. In addition, OPDs should also be involved as much as possible in the following:

- **Organisation of the workshop**, which may include deciding who should facilitate the workshop, participant lists, training location and venue, etc.
- **Accessibility and logistics** for the workshop, including help and advice on how to ensure reasonable accommodations of participants are met, recommendations for accessible training venues and services (e.g., sign language interpreters, captioning, etc.), coordinating complaints on accessibility issues that arise during the training, advice on budgetary and logistical issues concerning accessibility, advice on adaptation of materials for accessibility, etc.
- **Workshop delivery and expertise**, which may include advising on modifications to the content / materials, sharing experiences and stories during the workshop, advising on accessible facilitation, and/or serving as workshop facilitators, guest speakers, or moderators, for all or a portion of the workshop, etc.
- **Evaluating the workshop**, which includes participating in the overall evaluation of the workshop and providing specific feedback on accessibility of the workshop.

OPDs should play a key role in the Induction Workshop and should not be seen only as participants. For less experienced OPDs, advice on accessibility issues, participant lists, and logistics are a good starting point, but more experienced OPDs should play a more significant role in the facilitation and delivery of the workshop content.

## Situational Analysis

The Situational Analysis is a national contextual review to collect and analyse data on the national context through a multi-stakeholder process, including UN staff, government representatives, and OPD representatives. It is a key step in the planning process for UNPRPD programs but is also a useful tool that may inform UN and government planning processes beyond UNPRPD programming.

UNCTs should prepare the Situational Analysis in close partnership with OPDs to ensure that the UNCT and its partners develop UNPRPD programs based on the national challenges and priorities. OPD representatives, including women with disabilities and underrepresented groups of persons with disabilities, must be strongly represented as essential participants and must be proactively engaged in dialogue on the contextual factors as well as the discussions on program priorities. This is because persons with disabilities, including OPDs with very limited capacities, know best which priorities are most important to persons with disabilities based on their lived experiences.

The Situational Analysis will be delivered through a series of workshops, forums, or meetings facilitated by a consultant. OPDs should play a **co-creation/ co-facilitation role in the logistics, planning, and decision-making of all sections of the Situational Analysis**, including assisting in designing the process, planning the meetings/ workshops, monitoring accessibility during the process, and co-facilitating the discussions. Importantly, diverse OPDs must be actively engaged in providing information and evidence of the situation in the country and the selection of priorities of persons with disabilities in the country, based on UNPRPD's template. It is important to ensure OPDs are remunerated for their role in co-collaboration and co-facilitation.

Following meetings/ workshops, OPDs must be involved in **commenting on the draft Situational Analysis before it is finalized** and participating in the **validation process** on the content submitted to UNPRPD and should be **informed on the final version** submitted to UNPRPD. It is therefore critical that the consultant(s) facilitating the process are experienced in working with OPDs, ensuring their voices are heard, and facilitating co-creation processes with OPDs. UNCTs should also ensure that the process, including all meetings, workshops, and virtual communication, is accessible to persons with disabilities to enable their participation.

## Program design

Elements of the program design begin with the Situational Analysis, i.e., analysing the context to guide the focus of the program and deciding the priorities of the program. OPDs must play a key role in the program design elements of the Situational Analysis, as outlined above. The full program will then be fleshed out by completing the Full Proposal template, which will outline the program objectives, activities, outputs, outcomes, and budget. The proposal is informed by the priorities outlined and validated by OPDs in the situational analysis.

The Full Proposal should be carried out through a multi-stakeholder approach, including UN entities closely linked to the program priority, relevant government stakeholders, and diverse range of OPDs, including women with disabilities and underrepresented groups of persons with disabilities. While the UN Country Teams are the ones that receive UNPRPD funding directly and are accountable for program implementation, OPDs and other relevant stakeholders play an important role in the priorities of the disability movement. OPDs play an important role in validating the program priorities and selecting OPDs to take part in program activities. During the program design process, it is important for UN country teams to consider what kinds of decision-making mechanisms will be in place, how OPDs will be engaged in these decision-making processes.

UNCTs should consult with OPDs to complete the Full Proposal that draw on the learning from the Situational Analysis. After contributing to the development of the program through workshops and meetings, UNCTs should seek **validation and written feedback on the program design** from OPDs before submitting the Full Proposal to UNPRPD, and the **final version should be shared with OPDs** to keep them informed.

## Program implementation and monitoring

Program activities should be designed to ensure the meaningful and appropriate levels of participation of persons with disabilities and OPDs, including OPD-led activities. The modalities for partnering with OPDs on program activities will depend on the type of activities included in the program design as well as contextual factors, such as the capacities of the OPDs.

Possible modalities for ensuring engagement with OPDs in UNPRPD program activities should include:

- **Formal agreement** between the UNCT and OPDs to enable shared planning and decision-making with clear parameters of the project. This may include outsourcing specific responsibilities to OPDs, such as conducting disability audits, running inclusive meetings, developing / adapting communications and materials, managing or delivering program activities, etc.
- **Inclusive governance structure** made up of PUNOs and OPDs with shared decision-making responsibilities to oversee the program implementation and make decisions jointly.
- **Feedback groups or advisory committees** with OPD representation to formally input on specific outputs, e.g., on the design, revision, or development of policies or services in which OPDs, PUNOs and government can work collaboratively to provide technical guidance, advise and develop advocacy strategies together.
- **OPD-led or shared activities**, including taking the lead in developing, planning and managing a service, project, or program within UNPRPD programs. For example, training Sign Language interpreters, providing direct advice to persons with disabilities on social protection supports and benefits, etc. Shared activities are similar to OPD-led activities but involve joint responsibility with another partners, such as UN entities, government, private sector, university, or CSO.

- **Spaces for feedback, priority setting and multi-stakeholder dialogue**, may include the following:
  - **Facilitated workshops** that combine learning with discussion, innovation, and exploration of ideas. Workshops are ideal when initiating a project, taking stock of progress of the program, and generating input into outputs, such as laws, policies, services, strategies, and plans. Workshops provide space to work with multiple OPDs simultaneously, as well as other stakeholders, and can help to manage multiple and dissecting views.
  - **Constructive dialogues, forums, or round table discussions** to facilitate the exchange of ideas, debate key issues, or to bring together groups who either do not agree or who rarely engage with one another (e.g., OPDs and government or CSOs). It is a good modality for debate, as it brings an element of holding parties to account and can be a tool for resolving problems or conflict. In forums, debate is often free-flowing, or it may follow a pre-planned agenda. Round table discussions provide a space to debate where each participant has an equal right to participate. There are other formats, such as town hall meetings, which allow constituents to meet with decision-makers and debate key topics of interest.
  - **Focus groups** bringing together people with similar backgrounds or experiences to discuss a topic, often used in qualitative research. This modality works well when seeking information about perceptions, attitudes, beliefs, opinions, or ideas and can help to change services or programs to better meet the needs of a specific group
- **Capacity building** is a key aspect to UNPRPD programs, and some programs will have multiple capacity building activities, providing opportunities to tap into the knowledge and skills of OPDs as well as to build them. OPDs should be considered key providers of capacity building but may also be receivers of capacity building. This may include:
  - **Presentations, lectures, seminars, or webinars** that can be prepared quickly and delivered remotely to present a new topic or issue to an audience, update an audience on key information, or motivate an audience to take action. Elements of interactivity can be included through question-and-answer sessions
  - **Trainings, workshops, or courses** involving teaching new skills and behaviours, often through practical exercises, and imparting knowledge in order to deliver a particular activity, e.g., how to draft a policy. Disability sensitization trainings and workshops delivered by OPDs can be a key tool in tackling stigma
  - **Conferences** designed to share information on a specific topic to a large group are a good modality for combining learning with networking and informal, unstructured dialogue. OPDs can deliver workshops, plenaries, demonstrations/ simulations, discussions, information booths, etc. and can be key partners in the accessibility of the logistics. Their involvement should not be limited to disability-specific topics and should be considered for disability mainstreaming purposes as well
- **Direct technical assistance** involving expertise, instruction, skills training, transmission of knowledge, advice, or consulting services by an OPD or OPD representatives to an organization or government department on a specific technical area. This can include program reviews, strategic planning, needs assessments, evaluations, program development, and

other forms of advice. It is a good modality for helping governments and other stakeholders to understand how to reach persons with disabilities, remove barriers, and implement effective policies and programs.

- **Written feedback on draft programs, policies, and plans**, often in multiple stages is a common way to engage with OPDs and other stakeholders. Most often, these policies, plans, and programs are developed in-house and shared with OPDs for input. Feedback sought can be general or specific, such as reviewing a mainstream policy with an accessibility lens. If OPDs are going to engage at a later stage of the process, then it is best reserved for processes where very little input is required or where only minor improvements can be made. This modality is prone to misuse, i.e., used when a more engaging modality is required and UNCTs should listen to feedback from OPDs if they raise complaints regarding the modality used.
- **Surveys** to gather very specific information from a large group, such as OPDs and their constituencies, to better understand trends in the targeted group. Many can be sent electronically with a deadline and therefore used to gather information quickly. Because engagement is limited, it should only be used in situations where a limited amount of information from the participants is needed, yet is helpful, e.g., gauging opinions, characteristics, behaviours, etc. It is often used with other modalities, such as gathering ideas for workshop topics for an upcoming conference.
- **Advocacy and accountability** activities on issues and topics important to OPDs. One of the main functions of OPDs is to advocate for the rights of persons with disabilities and to hold governments and other actors to account. It is important to engage with OPDs as both a recipient of advocacy, i.e., to listen to and consider their policy positions on UN policies and priorities, and as an enabler and facilitator of civil society, i.e., in encouraging governments to engage with civil society actors on government policy and priorities. OPD-led advocacy activities should be built into UNPRPD programs, which may include advocacy meetings or meetings with decision-makers, public campaigns, research and evidence gathering, media work, etc.
- **Consistent and clear communication with OPDs to ensure they are informed** is important throughout every modality of UNPRPD programs. This can be done through listservs, newsletters, emails, meetings, etc. and tend to be less interactive but important for transparency. It helps OPDs to understand how their information was put into practice and may lead to other opportunities for further engagement. This modality is most effective when used with other modalities to avoid tokenism.
- **Monitoring and evaluation activities** to assess the effectiveness of UNPRPD programs, including supporting data collection and providing feedback.



# Annex I: Identifying and selecting OPDs

It can be tricky differentiating OPDs from other civil society organizations and disability service providers. In addition, as with other civil society organizations, some OPDs are not well-managed or may not represent diverse views of persons with disabilities within the country. Below are questions to consider when identifying and selecting OPDs for engagement:

Questions to consider	How to interpret the answers
<p><b>Is the organization governed, led, and directed by persons with disabilities?</b></p> <ul style="list-style-type: none"> <li>• <b>Is the organization’s membership comprised by a majority of persons with disabilities?</b></li> <li>• <b>Is the organization’s board or governing body comprised by a majority of persons with disabilities?</b></li> </ul>	<p>If the answer is no to any of the questions regarding the representation by persons with disabilities, then the organization is not representative of persons with disabilities and therefore not an OPD.</p>
<p><b>Is the organization’s aim to promote or pursue the rights of persons with disabilities?</b></p>	<p>This can be found by looking at the organization’s mission, activities and communications. If the organization promotes a medical or charity model, rather than a human rights model, or if the organization does not support the CRPD, then their values may not align with the UN.</p>
<p><b>What constituency(ies) among persons with disabilities are reflected in the organization (e.g., types of disabilities, gender, religion, ethnicity, age, geographic location, etc.)?</b></p>	<p>It is best practice to work with diverse groups of persons with disabilities, but some OPDs have been set up to focus on specific groups. Many cross-disability OPDs also struggle to understand how to be more diverse. If an OPD is not fully diverse, this should not be a reason to not engage with them. However, asking this question will help in planning to reach diverse groups of persons with disabilities. If the OPD does not represent a diverse constituency, then it may be necessary to work with several OPDs to ensure that marginalized groups of persons with disabilities are being reached. Informal networks can be created for this purpose.</p>

<p><b>Is the OPD independent from political parties? Is there transparency in governance?</b></p>	<p>Much depends on the political landscape of the country and the nature of the engagement being sought with the OPD. In some cases, links with a political party may completely undermine an OPD's independence. In other cases, it may be a factor to simply monitor during the engagement. It is also important to understand the governance structure of the organization to see if there is transparency, distribution of power, succession planning, opportunities for leadership development and that multiple perspectives are represented.</p>
<p><b>Is there evidence, including anecdotal evidence, that the OPD may be mismanaged or fraudulent?</b></p>	<p>Donors that are supporting OPDs can often verify fraud or mismanagement. If fraud or mismanagement has been verified and is either recent or is a long-term problem, it is best to not work with them, even if the relationship being sought is not financial. OPDs with mismanagement issues may not be representing their constituencies honestly, may be too distracted to follow through with the engagement, or may use UN engagement as a means of seeking funding from other donors. Due diligence checks should be carried out if there is anecdotal evidence of fraud or mismanagement.</p>

Many of these questions can be answered by the OPD itself, but it is good practice to check with others who have worked with them, such as civil society organizations, government bodies, other UN entities, other OPDs, donors, etc. if you are working with a OPD for the first time.

## Questions to consider when choosing umbrella and cross-disability OPDs

The questions below will help to determine a strategy for choosing OPDs that are best placed to represent all persons with disabilities.

<p><b>Questions to consider</b></p>	<p><b>How to interpret the answers</b></p>
<p><b>Does the OPD represent a range of persons with different kinds of disabilities? How large is the membership?</b></p>	<p>If yes, then it is probably a cross-disability OPD. It is best to check with them if they have a specific thematic or constituent focus. The number of members may indicate how representative they are compared with other OPDs operating in the country.</p>

<p><b>Does the OPD represent a range of member organizations, each of which represents one or more related disabilities? How many persons with disabilities are they reaching through their members?</b></p>	<p>If yes, then it is likely an umbrella OPD. It is best to look at how many member organizations they have and which OPDs are represented within their membership. If only a few of the existing OPDs are members, then they may not be very representative, but this may depend on how far-reaching the umbrella OPD's members are.</p>
<p><b>How many types of disabilities are represented in the OPD? Which types of disabilities are not represented in the OPD?</b></p>	<p>Request a breakdown by gender and type of disability of the leadership (including the board), the membership, and staff. If there are only two or three disability groups represented, then the OPD may not be representative. Look specifically for the groups that are commonly underrepresented. Also, if the organization is largely run by men, it is unlikely that the views of women are being heard.</p>
<p><b>What are the processes to ensure that all types of persons with disabilities are involved in consultation, decision-making, and monitoring processes?</b></p>	<p>Consider the measures they have taken to address the gaps in representation, as most OPDs struggle with representation. If they have developed specific mechanisms, such as committees, specialist staff, consultants, or other OPDs to help them address their gaps, then they may be more diverse than they appear. If they seek to ensure that all groups participate in important decision-making processes, then they may also be more representative than they appear. If the OPD is defensive or has no measures in place to be more representative, then it may be best to either work with another OPD or fill in the gaps by developing partnerships with supplementary OPDs or groups.</p>
<p><b>How many organizations claim to be an umbrella OPD in the country?</b></p>	<p>If there is more than one, it may be possible to work with both. However, it is important to conduct due diligence, as multiple umbrella OPDs may be the result of splintering.</p>

## Global level OPDs

At the global level, the International Disability Alliance (IDA) is a network of eight global and six regional organizations of persons with disabilities, representing over 1,100 OPDs in 182 countries: [www.internationaldisabilityalliance.org](http://www.internationaldisabilityalliance.org) (see Annex I for a list of regional level OPDs). In addition to IDA, there are a number of global level organizations of persons with disabilities (OPDs):

Disabled Peoples' International (DPI): <http://dpi.org/>

Dementia Alliance International (DAI): [Home | Dementia Alliance International](#)

Down Syndrome International (DSI): [Down Syndrome International \(ds-int.org\)](#)

Inclusion International (II): [Home - Inclusion International \(inclusion-international.org\)](#)

International Federation of Hard of Hearing People (IFHOH): [IFHOH - International Federation of Hard of Hearing People](#)

International Federation for Spina Bifida and Hydrocephalus (IFSBH): [IFSBH - International Federation Spina Bifida and Hydrocephalus \(ifglobal.org\)](#)

Transforming Communities for Inclusion (TCI): [TCI Global – Transforming Communities for Inclusion \(TCI\) \(tci-global.org\)](#)

World Blind Union (WBU): [World Blind Union](#)

World Federation of the Deaf (WFD): [Home Page - WFD \(wfdeaf.org\)](#)

World Federation of The Deafblind (WFDB): [WFDB – The World Federation of The Deafblind](#)

World Network of Users and Survivors of Psychiatry: [World Network of Users and Survivors of Psychiatry | International Disability Alliance](#)

## Regional OPDs

Regional OPDs advocate at the regional level, represent their region in international fora, and build the capacity of OPDs in their region. They are often comprised of continental OPDs focusing on a specific group or issue, sub-regional OPDs, and national umbrella OPDs. For UNPRPD multi-country programs that focus on a specific region, UNCTs should work with regional OPDs on regional-level engagement and national OPDs on national level engagement. However, regional OPDs can also provide:

- Information and guidance on working with national umbrella OPDs in their region
- Insight on issues that are cross-border or critical to the region, particularly where national OPDs may not be operating (i.e., there is a gap on an issue by national OPDs)
- Information and advice on regional bodies, policies, and monitoring mechanisms
- Information on how national OPDs engage in international fora.

Therefore, regional OPDs can serve as advisors, liaisons, and interlocutors for engaging with national OPDs and should be the main point of contact for regional level engagement. Below is a list of regional OPDs:

- African Disability Forum (ADF): [African Disability Forum](#)
- ASEAN Disability Forum (ASEAN-DF): [Home - Asean Disability Forum](#)
- Arab Organization of Persons with Disabilities (AOPD): [Arab Organization of Persons with Disabilities | International Disability Alliance](#)
- European Disability Forum (EDF): [Homepage - European Disability Forum \(edf-feph.org\)](#)
- Latin American Network of Non-Governmental Organizations of Persons with Disabilities and their Families (RIADIS): [Riadis | Red Latinoamericana de Organizaciones – Red Latinoamericana de Organizaciones](#)
- Latin American Network of Psychosocial Diversity (Redesfera Latinoamericana de la Diversidad Psicosocial): [Inicio | Redesfera Latinoamericana de la Diversidad Psicosocial](#)
- Pacific Disability Forum (PDF): <https://pacificdisability.org/>

## **Annex II: Examples of meaningful participation in UNPRPD Fund programs**

### OPD engagement in multi-stakeholder dialogues

In Viet Nam, the UNPRPD program enabled OPDs to engage multi-stakeholder partnerships and dialogues by facilitating collaborations with Government offices and Ministries. These partnerships were established to encourage dialogue and consultations on disability-inclusive policies and programs, bringing together government departments, OPDs, and other interested parties. For example, through the UNPRPD program the Viet Nam Federation of the Disabled organized a consultation workshop in partnership with the General Statistics Office to create disability inclusive output indicators to be included in the National Survey on Persons with Disabilities in 2023.

### OPD engagement in UNPRPD program design and coordination

The program in Montenegro, established a consortium of seven OPDs to coordinate program implementation including an organization of self-advocates representing the rights of persons with intellectual disabilities. Through the consortium, OPDs drafted an assessment of disability inclusion and meaningful participation of persons with disabilities in the Common Country Analysis to help ensure the UN Sustainable Development Cooperation Framework is disability inclusive.

### Engagement in policymaking

In Tanzania, the UNPRPD program engaged diverse OPDs to provide inputs on the development of the Zanzibar Person with Disability Act, to replace the Persons with Disabilities Act of 2006. To do this, the program brought together 156 OPD representatives (104 women and 52 men) from 12 OPDs to provide inputs on the draft Act so that it better aligns with the CRPD and promotes gender equality. The Act was adopted in 2022 and OPD representatives were also part of a technical committee that provided support to the Office of First Vice President and National Disability Council on implementation of the new Act.

### OPD engagement in technical advisory committees for law and policy

The UNPRPD program in Georgia created a technical advisory group with PUNOs and the National Network of Women with Disabilities to review and propose amendments to national sexual and reproductive health laws to ensure the multiple and intersecting forms of discrimination women and girls with disabilities face were addressed in compliance with the CRPD. Through the technical advisory group, women with disabilities drafted amendments to prohibit discrimination on the basis of disability, ensure provision of reasonable accommodations and protect a person's right to informed consent.

OPD Engagement in national development forums to implement SDGs: In Rwanda, the National Union of Disability Organisations of Rwanda (NUDOR) was appointed as an OPD focal point for the UN to ensure systematic participation of OPDs in the development, implementation and evaluation of the UN Sustainable Development Cooperation Framework.

OPD engagement in program design: In Moldova, the UNPRPD joint program supporting Ukrainian refugees with disabilities was shaped by the input and feedback received from women and girls with disabilities during the consultation workshops. During these consultations, women with disabilities identified barriers which were translated into concrete changes in the program's focus areas and initiatives.

OPDs as implementing partners working with PUNOs to jointly implement activities: UNFPA, one of the participating UN organizations implementing the UNPRPD joint program in Moldova, created an implementing partner agreement with the Alliance of Organisations for Persons with Disabilities for this national OPD to conduct trainings with front line service providers on the needs of persons with disabilities including the needs of refugee women and girls with disabilities with a focus on GBV prevention and access to sexual and reproductive health services.

OPDs carrying out research jointly with PUNOs: In Colombia, the UNPRPD program worked with OPDs to develop 2 knowledge products on meaningful participation of OPDs. The first was an analysis of challenges to meaningfully participate in decision-making spaces. The second knowledge product was a checklist of good practices to foster meaningful participation of persons with disabilities. Various OPDs actively participated in the research for these documents led by the Coalition for the implementation of the CRPD in Colombia.

## Annex III: Steps for successful engagement of OPDs in programming<sup>7</sup>

1. Based on experiences of PUNOs implementing UNPRPD programs and in consultation with OPDs, UNPRPD developed these essential elements for meaningful participation of OPDs in programs: **Begin planning early: Define** your objectives and outcomes you hope to achieve through engagement and participation.
2. From your objectives and outcomes, decide **what level of engagement you hope to achieve**. According to the participation continuum, to engage in a two-way relationship or partnership, what information and resources do you need to do this effectively? Who do you need to work with to do this effectively?
3. **Define roles of OPDs clearly** and set expectations for engagement. What role will OPDs play in the program concretely and what is the timeframe and budget for this engagement? How will you communicate the roles and expectations clearly? Can you establish a Memorandum of Understanding or Terms of Reference?
4. **Assess what you need to enable meaningful participation:** Do you have the resources and expertise to plan and implement a fully accessible and inclusive process? Do you need to bring in facilitators and other advisors with skills and understanding of disability rights to facilitate inclusive and accessible processes? Do you have contacts for service providers you can procure to provide accessibility accommodations for meetings and communication?
5. **Identify which OPDs you want to engage.** Do you want to work with national level OPDs or local OPDs? For what purpose (identify the areas of work you want to engage in such as law and policy reform, climate change, data collection, service reforms etc.)?
6. **Choose the right methodology for engagement** depending on the level of engagement you hope to achieve (technical advisory committees, implementing partners, multi-stakeholder coordination etc.).
7. **Plan ahead to ensure accessibility and reasonable accommodations for a diversity of persons with disabilities.** This includes having budgets for accessibility and accommodations and time to plan and learn what is needed, procure the rights service providers and make time to get feedback and inputs from persons with disabilities to see if changes or adjustments are needed.

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<sup>7</sup> This checklist was adapted from UNDIS Guidelines for Consulting Persons with Disabilities: [un\\_disability-inclusive\\_consultation\\_guidelines.pdf](#)



# Annex IV: Examples of meaningful engagement for each stage of the UNPRPD process

## Expression of Interest

- Formal partnership agreement between UNCTs and a national OPD, ideally the national umbrella organization representing a large constituency
- Signed letter of endorsement from a national umbrella OPD

## Induction phase

- Planning of the workshop carried out jointly with OPD partner including identifying facilitators from the disability movement to co-facilitate
- Accessibility and logistics for the workshop are planned and coordinated with the OPD partner
- Workshop delivered jointly with the OPD partner providing guidance on content, accessibility, facilitation and persons with disabilities are invited to be facilitators/moderators
- Evaluating the workshop jointly

## Situational analysis

- OPDs representing the diversity of the disability movement, are consulted during the situational analysis to gather inputs and reflections as well as priorities and strategies to inform the recommendations
- OPDs are consulted to provide inputs on and feedback to the draft situational analysis
- Focus group discussions are organized with members of OPDs from the national umbrella as well as other OPDs from outside the capital to gather qualitative data on the situation of persons with disabilities
- The validation workshop for the situational analysis involves the diversity of OPDs to validate the priorities and develop recommendations jointly

## Program proposal

- Program priorities are selected in consultation with OPDs
- Program proposal is developed in consultation with OPDs engaged in the situational analysis and at a minimum, with the OPD partner from the EOI
- OPDs review the final program proposal
- Program proposal

## **Program implementation**

- Formal partnerships are established with OPDs with clear roles and mutually agreed goals
- Program governance structure is in place in which OPDs play decision-making roles
- Programs are designed to support meaningful engagement of OPDs in a systematic way so that OPDs can input on various stages of legal and policy reforms and changes in systems. Engagement is no longer ad hoc and informal but intentional and clearly defined
- OPDs are supported financially and technically to provide guidance and technical expertise
- Reasonable accommodations for inclusive engagement are budgeted so that OPDs can participate without barriers and the costs for these adjustments are covered
- Capacity building activities are planned and budgeted for OPDs to more effectively engage on policy dialogue and national development planning processes
- Outreach to diverse constituencies is planned within the program with sufficient time and resources
- Spaces for dialogue and coordination with PUNOs, OPDs and government are planned with sufficient time to enable meaningful engagement, feedback and communication
- Programs are supportive of local level OPD engagement by establishing committees to support local civil society and government stakeholders review national level policies and programs and/or development and humanitarian frameworks and develop local level action plans such as climate mitigation or adaptation plans

## **Monitoring and evaluation**

- OPDs have a clearly defined role in program monitoring and evaluation processes
- Mechanisms for feedback from OPDs are established and they are inclusive of diverse groups and fully accessible
- Monitoring structures are inclusive of and accessible to OPD partners
- A committee of OPDs is established to provide independent feedback on the UNPRPD program

## Annex V: Main learning on OPD participation in UNPRPD funded programs

Based on an analysis of UNPRPD Fund national programs through their annual reporting as well as an OPD engagement survey UNPRPD conducted in 2022,<sup>8</sup> there is a clear need to shift from ad hoc consultations with OPDs to more effective and meaningful partnerships that are developed to support engagement on an equal basis. While most UNPRPD programs carry out consultations with OPDs, they do not include defining roles within the program or developing concrete partnerships in which OPDs help to set priorities or advise on disability rights issues. Below are the main gaps and challenges in realizing meaningful engagement with OPDs:

- Lack of understanding by PUNOs on how to implement accessibility and reasonable accommodations in practice to enable fully accessible mechanisms for collaboration.
- OPDs often lack the language needed to engage in policy and systems change dialogue with UN entities and governments on an equal basis.
- This gap in understanding the language used by PUNOs and government is often seen as a capacity gap within the disability movement.
- However, there is potential for PUNOs to better leverage the expertise of persons with disabilities about the barriers they face, their perspectives on inclusion and priorities for change.
- Formal mechanisms for OPD participation are at risk of being seen as symbolic or being underutilized if they are not clearly defined and/or have only a limited scope for engagement.
- Power balances within partnerships and governance structures can make meaningful dialogue challenging without transparency and clear roles.
- More transparency is needed on formal partnerships between OPDs, governments and UN agencies so that there is clear communication and information about roles, time-frame for engagement, expected outcomes and funding to support the process.

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<sup>8</sup> UNPRPD Fund administers a survey to OPDs and UNCTs annually to understand how OPDs were involved in inception phase activities and gather perspectives on their experiences, challenges and successes in engagement.

# **Annex VI: How to work with the disability movement and the diverse ways the disability movement can be structured**

## **Working with membership based national umbrella structure and cross-disability OPDs**

One of the most efficient ways to reach a large number of persons with disabilities is to work with a national umbrella OPD. Umbrella OPDs often have a large membership base and seek to influence national policy for all persons with disabilities within the country. However, even these large OPDs struggle to represent the diverse perspectives of persons with disabilities. For example, a national umbrella OPD may not have a national member representing women with disabilities or persons with psychosocial disabilities. Cross-disability OPDs that are not membership based but organized to address disability rights broadly bringing together different groups of persons with disabilities can often fill this gap. However, it can be difficult to determine if any of these OPDs are truly representative of the diversity of the disability movement.

## **Ensuring representation of those most marginalized and underrepresented**

Reaching out to umbrella and cross-disability OPDs may not ensure that all groups are represented. It may be necessary to identify strategies to fill gaps by seeking participation from other OPDs (e.g., focusing on specific underrepresented groups). Where OPDs cannot be found, are not representative of diverse groups of persons with disabilities, or are not functioning, PUNOs can use informal approaches. This is most commonly needed in order to reach underrepresented groups that do not have an OPD to represent them. Informal groups, such as self-help groups or groups of service-users, and/ or key individuals from underrepresented groups may be consulted in these instances.

When working with OPDs that represent underrepresented groups such as persons with intellectual disabilities, autistic persons, deafblind persons or persons with psychosocial disabilities, it is important to ensure that the representatives from the OPD actually represent the constituent group to avoid staff without disabilities from making decisions or speaking on their behalf. Ask if the OPD is composed of and represents the views and opinions of the underrepresented group, despite having support from staff without disabilities (even extensive support from parents or persons without disabilities). For example, are they responsible for decision-making regarding finances, policy positions, and organizational priorities?

Parents' groups are a good resource for seeking input on children with disabilities. However, the views of parents should not be substituted for their children. Find out if the parents are representing children between the ages of 0-12 years and if they support the views, opinions, priorities, active participation and decision-making of their children. If they are not, then they may only be representing the views and needs of families of persons with disabilities. Families are important allies and have their own needs. However, these should not be substituted for the views and needs of persons with disabilities, regardless of the type of disability.

Some OPDs, including national OPDs, may struggle to cover the entire country, especially if there are geographic, historical or political barriers. It is not uncommon for OPDs to operate in the capitol city and have limited reach to rural or remote areas. To ensure that diverse geographic regions are included when engaging with OPDs, ask OPDs about the geographic reach of their membership. Develop a database and/ or map of OPDs to ensure that all regions are covered (e.g., through multiple OPDs) and be open to allowing more people to connect and participate to ensure a diversity of views.

### **Ensuring engagement with OPDs working at the intersection of disability and gender**

Building partnerships with representative organisations of women with disabilities and persons with disabilities of diverse SOGIESC<sup>9</sup> is important. The disability movement in many contexts has long been led by men with disabilities with limited leadership of women with disabilities or persons with disabilities of diverse SOGIESC. In many cases, issues around gender as well as sexual and gender diversity have not been prioritized by mainstream disability movement leaders. In many places, there is a limited number of membership-based organisations representing women with disabilities or persons with disabilities of diverse SOGIESC.

Cross-disability organisations that are not membership based may have representation from more diverse groups of persons with disabilities. For example, in many contexts there are non-membership-based organisations or collectives of women with disabilities who are not part of the national cross-disability federation or umbrella. There may be women “wings” or “sections” within national umbrella organisations but in general, there are very few mainstream disability organizations that include members of diverse SOGIESC. Disability activists who identify as LGBTQ+ have suggested that there is animosity from the mainstream disability movement in the forms of homophobia and transphobia. However, there may be other civil society organizations that persons with disabilities from marginalized groups may be participating in beyond the disability movement such as LGBTQ+ groups. Safely engaging marginalized individuals requires collaborations with organizations that are familiar with their lived experiences, the potential risks they may face, and appropriate strategies to minimise these risks.

When organisations or groups of women with disabilities or persons with disabilities of diverse SOGIESC are not represented through a national umbrella, it is preferable to go through organisations of persons with disabilities to ask for recommendations for diverse representation of persons with disabilities. UNPRPD Technical Secretariat can also provide contacts to women led OPDs, OPDs led by persons with disabilities of diverse SOGIESC as well as women and gender diverse leaders with disabilities working at the global level.

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<sup>9</sup> In many contexts where homosexuality and gender diversity are criminalized and where LGBTQ+ persons are threatened or attacked, organizations of persons of diverse SOGIESC may keep their organizational information confidential. It is important to remember the concept of “do no harm” in our work so that we don’t jeopardize the safety or security of project partners and participants.



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