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Guidelines for rights-based consultations with OPDs



Introduction

This guidance note provides practical recommendations to guide rights-based consultations with persons with disabilities. It aims to assist organisations to ensure meaningful participation and influential input of Organisations of Persons with Disabilities (OPDs).

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Key issues

Development and humanitarian stakeholders are becoming increasingly aware of the need to **consult and engage with the disability movement**, resulting in significant and positive outcomes for persons with disabilities in line with their rights under the Convention on the Rights of Persons with Disabilities (CRPD) ¹. At the same time, this increasing trend has not always been accompanied by appropriate resourcing to sustain OPDs' increased engagement in terms of time, funding, and other elements of capacity. ² This has led to significant challenges to effectively and meaningfully engaging OPDs in development and humanitarian processes and programs, in accordance with their rights.

There are other barriers to meaningful engagement of OPDs, due to factors such as: the **power imbalances** between OPDs and the stakeholders asking for their participation, different **communication styles** (for example, exclusion due to formal or written communication formats and settings, or where the stakeholder does not use the local language), or where the stakeholder does not address **accessibility requirements**.

Meaningfully partnering with and involving OPDs in decisions that affect them, means **recognising and responding to these challenges** faced by persons with disabilities in relation to meaningful participation. Moreover it requires development practitioners to go beyond a 'box ticking' approach to OPD engagement that only focuses on, for example, inviting OPDs to consultations or to attend events. Indeed, consultation done in this way can divert OPDs from their own priorities and exacerbate marginalisation.

Instead, **OPDs must be recognised as experts and leaders in the lived experience of disability**, and given opportunity to influence outcomes throughout investment or project cycles. This could include meaningful opportunities to contribute as co-decision makers, rather than just consultation participants. It must also be recognised that this requires both time and capacity, so investment must be made in the OPD remuneration for time given, core funding for the OPD (e.g., to facilitate their sustainability, and capacity development and technical advice to the OPD to support their ongoing contributions).

International frameworks on participation of persons with disabilities

- UNCRPD. (2006). [Article 4.3](#): Persons with disabilities and their representative bodies have the right to be consulted and actively involved in decision making processes that affect them.
- UNCRPD. (2006). [Article 32](#): International cooperation efforts should involve appropriate partnerships with OPDs.

Taking action

To empower persons with disabilities, practitioners should aim for transformative engagement with OPDs that is truly collaborative and achieves mutually beneficial outcomes, such as ongoing partnerships. More guidance on building transformative relationships with OPDs are provided in the resources section below.

It is important that all consultations with persons with disabilities and OPDs are rights-based. The following is a check list for undertaking such rights-based consultations ³ and should be explored alongside further resources on transformative engagement with OPDs. ⁴



Before inviting the OPD to the consultation

- **Do your own research first**

There are many guidance documents, training resources, and position papers available that have often been developed by, or with input from, OPDs. Prior research will free time within the consultation for participatory decision-making.

- **Plan for consultation to take place as early in the process as possible**

OPDs are often consulted at quite a late stage e.g., once a project has already been designed. This could make the consultation tokenistic if changes based on OPD feedback cannot be acted upon. Ensuring for consultations with OPDs take place during the design phase increases scope for meaningful input and participatory decision making by OPDs, based on their priorities and needs.

- **Consider who you are inviting**

Consultations should seek to include people with disabilities in all their diversity and be mindful of those often underrepresented (including people with psychosocial and intellectual disabilities, people who are d/Deaf or hard of hearing, those who may be particularly marginalised such as women or other minority groups with disabilities, etc).

In low-resource settings, especially at community level, self-help groups are often formed by persons with disabilities to support one another e.g., for livelihood activities. These group should also be considered for participation in any consultation on issues that affect them.



When inviting the OPD

- **Be flexible**

Make it explicit that the invitation to participate is optional and be flexible with times if possible.

Remember that there is often a significant power imbalance between your organisation and the OPD. Assure the OPD that you respect that they may have other constraints on their time, and while you wanted to ensure they were invited, they should feel free to prioritise other work if required.

Ask if there is an alternate format for providing their input that may suit them better (e.g., if they have an existing position statement on the topic, they could forward it to you, or you could schedule a phone call rather than hold a meeting).

- **Include remuneration for time**

Attending consultations and providing expert input is a professional function of OPDs and should be paid for accordingly. This is not only a matter of respecting the right to remuneration for work (Art. 27 CRPD), but also key to sustaining the financial viability of OPDs - providing input and consultations can take up a substantial amount of their time.

- **Ask what accessibility requirements and reasonable accommodations are needed and ensure these are met (Art 9 CRPD)**

Invitations for OPDs and persons with disabilities to attend consultations are tokenistic at best if members are not able to attend or participate due to access barriers, including inaccessible communication materials. Poor preparation can be damaging to organisational relationships and undermine the dignity and rights of persons with disabilities invited. Ensure you enquire about reasonable accommodations and ensure that those accommodations are provided for during consultations. See the [Listen, Include, Respect Guidelines](#) (2022) ⁵ for further guidance. Where possible, use local languages to improve accessibility.

- **Consider OPD capacity**

OPDs bring a wealth of lived experience to consultations. They may not, however, have in-depth technical knowledge on the sector you are working within. Meaningful consultation may therefore require providing some prior information and technical support (including training) to the OPD representative/s regarding the subject matter, so that they can better understand and engage in discussions.

- **Set clear objectives for the consultation**

Consultation objectives should be clearly defined, allowing OPDs to focus their energies on relevant contributions aligned with their own mission and priorities.

- **Consider most appropriate and safe setting for consultation**

Persons with disabilities may encounter barriers in participating in a broader group setting, particularly in relation to some topics (for example, family violence or access to justice) or if they experience marginalisation due to intersecting identities (e.g., women, ethnic minorities or members of the LGBTQIA+ community with disabilities), or are members of an underrepresented group (e.g., persons with psychosocial or cognitive disabilities). Planning engagements through safe spaces such as a peer-led consultation or discussions, and channels that allow levels of anonymity, can facilitate more meaningful engagement in such circumstances.



During the consultation with the OPD

- **Check in to ensure accessibility requirements are being met at all stages throughout consultation**

Failure to properly meet requested reasonable accommodations (including accessible communication formats) during the consultation leads to exclusion of the OPD from the consultation process - even if they are in physical attendance.

- **Ensure persons with disabilities are given opportunity to participate equally**

Negative or discriminatory attitudes regarding disability from other participants or facilitators, as well as communication and sensory barriers, may make it difficult for persons with disabilities to contribute. If it appears persons with disabilities are finding it difficult to participate equally, create intentional opportunities for them to do so, and check in with them about any barriers they may be encountering. Creating an environment where all participants feel valued and are encouraged to contribute will enhance outcomes.

- **Consider how consultations can facilitate participatory decision making**

OPDs should be valued as collaborators and joint-decision makers, rather than just informers or advisors. This means providing opportunity for persons with disabilities to share their own reflections and priorities, as well as responding to your questions. It also means involving OPDs in significant discussions that shape the project or program, rather than just contributing to context-gathering information.



After the consultations

- **Build an ongoing relationship with OPDs**

To ensure the interaction with the OPD is rights-based, not tokenistic or extractive, the relationship should be ongoing and mutually beneficial. This could be via networking and remaining a useful contact for the OPD. Provide your full contact details and invite them to contact you if they need assistance or introductions. Consider introductions or opportunities that may benefit the OPD.

- **Consider investing in the OPD**

This could involve financial investment, through flexible funding if possible, or through informal support such as providing writing support, mentoring or putting together joint proposals for opportunities like conferences.

- **Be an advocate for disability inclusion and ally for the OPD**

Disability inclusion and rights realisation will not be achieved if it is left only to OPDs to raise awareness. Advocate for disability inclusion practices within your sphere of influence e.g., with partners, donors, or NGOs. Identify where OPDs are not included in key sectoral decision-making opportunities (such as within partnerships and coalitions, key meetings, and dialogues) and broker an invitation for them, following the above principles.

- **Be open to continuous learning and improvement**

Evaluate consultations afterwards and remain open to feedback from OPDs about successes and challenges. This will ensure adaptation and improvement over time, fostering mutual respect.

Resources and further information

- International Disability Alliance. (2022) [Not just ticking the disability box? Meaningful OPD participation and the risk of tokenism](#)

This document presents and discusses the findings of **IDA's second Global survey on participation of Organizations of Persons with Disabilities**. It includes recommendations for achieving a transformational shift around participation in decision making and outlines how this will only be achieved by ensuring accelerated investments in the preconditions that enable OPD participation, as well as proactively planning and supporting participation of all persons with disabilities.

- International Disability Alliance. (2020). [Increasingly Consulted yet not Participating: Global Survey on Participation of Organisations of Persons with Disabilities in Development Programmes and Policies](#)

This document presents and discusses the findings of **IDA's first Global survey on the participation of OPDs** which sought to provide the unique perspective and experience of OPDs themselves regarding their participation in development processes. The findings highlight that, while consultation and formal involvement of OPDs is slowly increasing, the meaningful influence of this is often limited, as is OPDs' overall satisfaction with the ways they are able to be involved. It includes comprehensive sets of recommendations on how to better ensure meaningful participation of OPDs.

- United Nations. (2021). [Disability Inclusion Strategy Guidelines – Indicator 5: Consulting Persons with Disabilities](#)

This document provides guidance on how to consult with and **actively involve persons with disabilities in decision-making processes across the UN's work**. It provides guidance on how to make participation of persons with disabilities meaningful.

Guidance on building transformative relationships with OPDs

- CBM-Nossal Partnership for Disability-inclusive Development and Research for Development Impact Network. (2020). [Research for all: Making Development Research Inclusive of People with Disabilities](#). RDI Network, Canberra.
- Gibson, C., & Bokoff, J. (2018). [Deciding Together Shifting Power and Resources Through Participatory Grantmaking](#). Grantcraft, New York.
- Water for Women. (2022). [Partnerships for Transformation: Guidance for WASH and Rights Holder Organisations](#). Water for Women, Canberra.

Notes

- 1 UN General Assembly (2007). [Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007](#). Online. Accessed April 24, 2024.
- 2 International Disability Alliance (2022) [Increasingly Consulted yet not Participating: Global Survey on Participation of Organisations of Persons with Disabilities in Development Programmes and Policies, 2020](#). Online. Accessed April 24, 2024.
- 3 i.e. Recognising and honouring the rights of people with disabilities as set out in the CRPD General Principles, Art 5, 8, 27, 28, 29.
- 4 International Disability Alliance (2022) [Increasingly Consulted yet not Participating: Global Survey on Participation of Organisations of Persons with Disabilities in Development Programmes and Policies, 2020](#). Online. Accessed April 24, 2024.
- 5 Inclusion International and Down Syndrome International (2022). [Listen, Include, Respect](#). Online. Accessed May 1, 2024.