Engaging with organizations of persons with disabilities in humanitarian action

Tip sheet

Engaging organizations and informal groups of persons with disabilities in humanitarian action are one of the ‘must-do actions’ defined in the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action. This tip sheet presents some key steps for identifying and starting an engagement with organizations of persons with disabilities (OPDs) and provides tips for UNICEF staff and partners who are new to disability inclusion, including those who are implementing the humanitarian response.

What is an organization of persons with disabilities?

Organizations of persons with disabilities (OPDs) are any organizations or associations led, directed and governed by persons with disabilities that are committed to the Convention on the Rights of Persons with Disabilities (CRPD) and fully respect the principles and rights affirmed therein. Some OPDs represent persons with all impairment types, while others may focus on a particular impairment type, gender or sectoral issue. They may represent persons in a particular geographical area or belonging to an international or national network. While OPDs can be direct responders, they also play a critical role in representing the perspectives and priorities of crisis-affected persons with disabilities throughout the humanitarian programme cycle. This role must be recognized and supported to achieve effective locally-led responses. Jump to section on OPDs and their importance to humanitarian action.

Before engaging with OPDs it is essential to

Develop a basic awareness among UNICEF staff of the rights and capacities of persons with disabilities, including an introduction to OPDs.

Initiate an internal reflection process within UNICEF to define the specific purpose and scope for OPD engagement, which acknowledges the importance of flexibility and genuine partnership. This should involve a wide range of staff and partners to ensure shared ownership, understanding, and expectations.

It is advisable to seek support from a trained disability-inclusion focal point to facilitate this process.
STEP 1
Identify OPDs and informal groups of persons with disabilities in your location

Depending on the systems in place in the country or region, OPDs may be registered with the government; either specifically as OPDs under a dedicated category or within broader civil society registration. However, in some settings, OPDs may face barriers restricting their registration or be organized more as informal groups.

How to locate OPDs at:

- **International and regional levels:** Contact regional or global OPD networks for information on OPDs in your location. (International Disability Alliance hosts links to regional member OPDs websites and the Stakeholder Group of Persons with Disabilities.
- Contact the Reference Group on inclusion of persons with disabilities in humanitarian action, which is a platform for cooperation between UN agencies, International Agencies, NGOs, and OPDs in promoting disability-inclusive humanitarian response (Email: rg.disabilityinclusion@gmail.com).

- **National and local levels:** Disablity stakeholders, including individual persons with disabilities, government disability focal points, disability service providers and disability-specific NGOs may be able to refer you to OPDs:
  - In some instances, a contact list or mapping of OPDs may be available with these actors.
  - Use a ‘snowball’ approach to build on any initial contacts you have, to seek out more information on OPDs in your location.
  - Be mindful that OPDs may sometimes represent a smaller subset of the diversity within disability. Purposefully and proactively reach out to underrepresented groups, see Step 3.

If there are no available OPDs in your location or no OPDs adequately representing the affected population

In many humanitarian contexts, no local OPDs may exist; or where they do exist, they may have been weakened by the crisis or have limited capacity, may not adequately represent all persons with disabilities in a population, or may not have adequate availability, capacity or interest to engage in humanitarian response.

- In refugee and other displacement contexts where there are no OPDs, it may be appropriate to engage with the host community. In this case, carefully consider their prospective role and support them to include displaced persons with disabilities. For example, host community OPDs may be engaged to give advice on accessibility or to facilitate disability inclusion awareness for staff but not to express the requirements and priorities of the displaced population.
  - In displacement contexts, identify, support, and engage local informal groups of refugees and/ or internally displaced persons with disabilities. Informal groups can be located by asking persons with disabilities, community leaders, and disability service providers and then using a ‘snowball’ approach to locate informal groups or self-help groups.
  - Support persons with disabilities from affected populations to self-organize in groups and networks.
  - Ensure that persons with disabilities are included in existing community leadership committees and other community engagement mechanisms.¹

¹ Relevant resources include: UNICEF Accountability to Affected Population Handbook; Save The Children guidance on inclusive feedback and reporting mechanisms; IRC guidance on inclusive client responsiveness.
In many cases, one OPD may not adequately represent all persons with disabilities in a population. Under-represented groups of persons with disabilities, including persons with psychosocial disabilities, persons who are deaf-blind or who have intellectual disabilities, are less likely to be represented by OPDs. Other persons with disabilities that might not be fully represented among OPDs include refugees and internally displaced persons, as well as women, children, indigenous persons, and people of diverse gender expression and sexual orientation.

- Complement engagement with OPDs by proactively looking in the affected population for people from these underrepresented groups and supporting them to share their concerns and ideas on how to make humanitarian assistance inclusive for them.
- Raise awareness among UNICEF and partner staff, and where appropriate with OPDs, on the needs and priorities of underrepresented groups.
- UNICEF can encourage umbrella and cross-disability organizations to be more diverse and representative by prioritizing engagement with OPDs that are diverse and work with underrepresented groups.
- Women and girls with disabilities may face difficulties in accessing OPDs. Support women with disabilities to participate in organizations and promote the participation of women and girls with different types of disabilities in consultations and OPD engagement. Provide for their safe participation and assess protection risks so as not to expose them to any undue risk. This can be supported through accompaniment by family or friends, ensuring safe accessible transport, holding meetings during daylight hours and close to participants’ homes, and conducting specific consultations with women and girls as relevant.

Agree with the OPDs on the type of engagement

- Before meeting with an OPD consider the various roles that OPDs can play (jump to the relevant section below).
- Where possible, gain some knowledge about the OPD before the meeting, asking them to share information about their mandate, membership, their main activities, and if they have previous experience on humanitarian engagement.
- During initial meetings, provide OPDs with the opportunity to clarify their priorities, and be clear about what, if any, support is required for effective engagement, both in terms of reasonable accommodation for individuals, as well as organizational support.
- Reflect with the OPD on the scope of engagement and the roles of OPDs within a given humanitarian crisis.
- Invite OPD representatives to be guest speakers at staff meetings, training, or other relevant planning meetings or events at your agency, to raise awareness of their role and capacities.

Facilitate ongoing engagement and consultation with OPDs

Engage with OPDs and persons with disabilities requires investment in accessibility, including on inclusive communication requirements. This has some budget implications, which could be added into projects under a line on accessibility or reasonable accommodation, or potentially, inclusive community engagement. Some practical tips and further guidance to facilitate engagement include:
• Ensure that any facility or venue used for meetings with partners is accessible (e.g., step free or ramps, easy to reach including for persons with reduced mobility, accessible sanitation and hygiene facilities).  
• Enable remote engagement and consultation by supporting access to the internet and mobile devices for OPDs who might have limited resources, particularly for reaching out to their members in remote locations. Also, support informal groups to access the internet for engagement as relevant.
• Ask OPDs for any specific communication requirements and having a budget available to provide sign language or other support.
• Plan for additional time for organizations to reach out to their members in situations of crisis and emergencies, particularly underrepresented groups such as persons with intellectual disabilities.

**STEP 5** Appropriately resource OPD engagement

Adequately reimburse OPDs for their time and expertise. This includes covering the cost of reasonable accommodations where required. For example, if an accessible taxi is required to attend a meeting consider providing transport, payments for a personal assistant, hiring sign language translation or adapting your meeting venues.

Additionally, remember that many OPDs and their members may not be aware of humanitarian infrastructure. Providing basic information and training on humanitarian systems and processes will support OPDs to provide meaningful inputs and advice around disability inclusion.

**STEP 5** Establish systemic engagement with OPDs including longer-term partnerships

The localization commitments in the Grand Bargain implore humanitarian actors to take a longer-term approach for working with local actors including OPDs. It is important to establish systemic, meaningful, mutually reinforcing collaboration with OPDs beyond an often-short humanitarian cycle. Ways to do this include:

• **Partnership:** Provide information to OPDs on partnership procedures and programme management standards. Remove barriers to partnerships and engage OPDs in project steering committees and governance bodies.

• **Capacity strengthening:** Invest in the institutional capacity of OPDs. Support the formation of formal and informal groups of persons with disabilities.

• **Coordination:** Leverage UNICEF engagement in national systems to support OPDs to engage in national emergency preparedness and response mechanisms.

• **Financing:** Explore opportunities to provide funding to OPDs on mutually agreed priorities, including providing accessible information on funding/partnership processes.

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2 There are numerous resources available on how to conduct accessible and inclusive meetings, focus groups, consultations etc., some of them are listed under Section 3 in UNDIS Guidelines Consulting persons with disabilities Indicator 5: pp. 17-33. For inclusive language and communication, read more in UN Disability Inclusive Communication Guidelines 2021. There are also relevant UNICEF resources including a training module on inclusive communication and brief guides on accessible events and documents.

3 Relevant resources: UNICEF Accessibility Toolkit, Tips on accessible remote meetings (Internal UNICEF); DARU micro-course on accessible online meetings.
Understanding OPDs and their importance to humanitarian action

**What is an OPD?**
OPDs are any organizations or associations led, directed, and governed by persons with disabilities that are entrenched, committed to, and fully respect the principles and rights recognized in the CRPD. Some OPDs represent persons with all impairment types, while others may focus on a particular impairment type, gender, sectoral issue, or represent geographical areas (local, provincial, national, regional or international).

**What is the mandate of an OPD?**
OPDs play a critical role in representing the viewpoints of persons with disabilities. They are established predominantly to collectively act, express, promote, pursue and/or defend the rights of persons with disabilities and bring a unique perspective to speak on their behalf. Not all OPDs have a mission that aligns with humanitarian action. In many cases, OPDs will not have engaged with the humanitarian sector and the humanitarian architecture. Often, they have had few opportunities to partner and collaborate with humanitarian organizations.

**Are OPDs and disability-specific organizations the same?**
OPDs are distinct from organizations ‘for’ persons with disabilities. Disability-specific civil society and international organisations (for example HI, Sightsavers, or CBM Global) provide humanitarian services and/or might engage in advocacy on disability rights, but do not have leadership primarily made up of persons with disabilities and therefore are not viewed as OPDs.

**Why should we engage OPDs?**
The disability rights movement slogan, ‘nothing without us’, urges humanitarian agencies to ensure the active participation of persons with disabilities in all steps of programming – from planning to implementation, to evaluation. Partnerships and collaboration with OPDs improve the effectiveness and accountability of humanitarian operations as OPDs are best qualified to provide information on the challenges they experience and to provide informed input to strengthen the quality of inclusive practice. In addition, meaningful engagement with OPDs aligns with commitments towards localization, accountability, and inclusion.

**What roles can OPDs play in humanitarian action?**
OPDs may take on different roles, depending on their capacities, representation, resources, and strategic interest. Some common roles are:

- Providing information on where persons with disabilities are located, their situation, barriers that prevent their access to humanitarian assistance, threats to them and violations of their rights.
- Providing technical support on disability inclusion to humanitarian organizations, such as advising on local solutions for accessibility.
- Raising awareness of disability among humanitarian sectors.
- Reviewing programme documents, guidance and tools, and advising on strengthening disability inclusion.
- Reaching out to more marginalized persons with disabilities, further increasing the reach of programmes.
- Conducting accessibility audits on facilities, information and communications tools and material.

**Other resources:**