

Disability Inclusion Helpdesk Report No: 116

Query title	Engaging organisations of persons with disabilities in humanitarian crises
Authors	Miglio, V. and Buchanan, J.
Date	8 th July 2024
Query	<ol style="list-style-type: none"> 1. What is the evidence on how OPDs are responding to meet the needs of persons with disabilities in humanitarian crises? What types of support do OPDs require to do so? What challenges do they face? 2. What are the mechanisms and ways to reach OPDs (both within UN humanitarian system, and via civil society)? 3. What are the barriers to OPDs and persons with disabilities participating in/influence over humanitarian decision-making, and any good practice in addressing these?
Enquirer	Women and Girls and Humanitarian Departments

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1. Overview

People with disabilities are disproportionately impacted by humanitarian emergencies and face disproportionate barriers in accessing humanitarian assistance. A 2015 report by Humanity & Inclusion (2015) found that 75% of respondents with disabilities living in humanitarian contexts did not have access to basic assistance such as water, shelter, and food. The past decade has seen some progress in recognising the need to consider disability inclusion in humanitarian frameworks, policies, and guidelines. However, additional efforts are needed to translate these commitments in practice. Organisations of Persons with Disabilities (OPDs) are key players in this respect as they have the necessary expertise, local knowledge and networks, and can support humanitarian actors in improving the effectiveness and accountability of their operations through improved disability inclusion and mainstreaming.

This evidence review, informed by desk review and consultations with OPDs and disability inclusion experts, outlines effective funding mechanisms for and approaches to working directly with OPDs in humanitarian crises. This product was produced through the Disability Inclusive Development (DID) Helpdesk, a research and advice service on disability inclusion for FCDO and other UK government departments.

OPD Action in Humanitarian Response

OPDs adopt diverse roles and functions in crisis contexts, including but not limited to: delivering technical guidance on disability inclusion to humanitarian stakeholders; removing barriers to access humanitarian assistance; collecting data, conducting needs assessments, and providing information on the situation of people with disabilities in emergency contexts; advocating for the rights of people with disabilities, including humanitarian architecture and Humanitarian Response Plans; and delivering humanitarian assistance to people with disabilities (e.g., psychosocial support and in-kind assistance) (CBM International, HI and IDA 2019).

OPDs face a range of organisational and system-wide barriers when engaging in humanitarian action. Firstly, OPDs remain largely under-resourced, which limits their capacity to deliver humanitarian support and to engage in humanitarian response in other ways, including advocacy. In addition, when crisis strikes, many OPDs may not have previous experience of engaging in humanitarian action, affecting their ability to identify entry points into the sector and its consultative bodies. In addition, consultative bodies are often not accessible to people with disabilities and their representative organisations, which further restricts OPD action in humanitarian response. Finally, there are gaps in the preconditions for disability inclusion in the sector. There is a need to build the knowledge of humanitarian stakeholders to meaningfully engage people with disabilities and their representative organisations, and ensure sufficient resources are available to address barriers to participation.

Outreach to OPDs and Funding OPDs

There are a number of established avenues through which regional, national, and local OPDs can be identified at global, regional and local levels. These include: the Reference Group on Inclusion of Persons with Disabilities in Humanitarian Action; global, regional, and national umbrella OPDs; the humanitarian clusters system; thematic working groups; and existing mailing lists and mappings of OPDs. When engaging OPDs through

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established consultative bodies and structures, it is necessary to be aware of the extent to which they are accessible and representative of different constituency groups, paying specific attention to impairment groups that are commonly marginalised in the disability movement, such as persons with intellectual disabilities, persons with psychosocial disabilities, and persons who are deaf and who are deafblind.

This evidence review identified limited existing examples of successful funding partnerships between donors and OPDs, highlighting the previous lack of focus on this area in the sector. Recommendations for improving funding partnerships with OPDs include: improving the accessibility of funding applications (e.g., language, formats, hosting platforms), streamlining funding requirements (e.g., due diligence, history of audits), and improving the flexibility and length of available funding opportunities.

OPD Engagement in Humanitarian Decision-making

There is limited evidence of the systematic and meaningful engagement of OPDs in humanitarian decision-making by governments, funding agencies, and other key humanitarian stakeholders. More effort is needed not only to consult people with disabilities and their representative organisations on disability-specific issues, but also to embed their leadership and participation in broader decision-making structures to support the effective delivery of equitable humanitarian assistance and ensure the mainstreaming of disability inclusion across humanitarian activities. This is in line with the FCDO's Disability Inclusion and Rights Strategy, as well as messaging from the disability rights movement: "nothing without us, because everything is about us."

2. Introduction

Worldwide, there are an estimated 1.3 billion people with a disability. This corresponds to 16% of the world's population or 1 in 6 people (WHO 2023). The UN Convention on the Rights of Persons with Disabilities defines disability as those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. Under this definition, it is barriers in society which are disabling, rather than disability being understood through a medical lens. It is increasingly recognised that people with disabilities are disproportionately impacted by climate-related disasters, conflict, and other humanitarian emergencies. Crisis conditions exacerbate the pre-existing attitudinal, environmental, and institutional barriers that people with disabilities face in their daily lives. For instance, it is estimated that in emergency contexts mortality rates among people with disabilities may be up to four times higher than among the general population (UN DESA 2016).

In addition to the direct impact of crises, people with disabilities frequently encounter barriers to accessing humanitarian assistance on an equal basis with others. This often results from a lack of accessible information on existing humanitarian services and the limited accessibility of services and assistance themselves (Humanity and Inclusion 2015). The number of people with a disability often increases in emergency situations because of new injuries, a lack of quality medical care, or the collapse of essential services (Humanity and Inclusion 2015), as well as psychological impacts.

Consistent with human rights obligations to ensure the meaningful consultation and participation of people with disabilities, humanitarian actors must consistently take steps to ensure an inclusive response in crisis settings. People with disabilities are

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those best placed to know about the barriers they face and contribute to solutions that respond to their self-defined needs and priorities (CBM International, HI & IDA 2019). To achieve meaningful participation, disability inclusion principles should be embedded across all stages of humanitarian preparedness and response, including the planning, design, implementation, and evaluation of humanitarian interventions. Humanitarian mechanisms should be accessible to persons with different types of impairment, including those most likely to be most marginalised due to type of impairment or due to intersecting forms of discrimination including on the basis of age, sexual orientation and gender identity, race, religion, geographic location, migration status or other factors, in order to ensure their meaningful participation and leadership. The legal and policy framework regarding the engagement of people with disabilities and their representative organisations in humanitarian action is outlined at the end of this section. More guidance can be found in the [FCDO Programme operating framework \(PrOF\) guide: Engagement & consultation with organisations of persons with disabilities](#).

OPDs play a critical role in representing and advocating for the perspectives and priorities of crisis-affected people with disabilities in humanitarian settings. OPDs are commonly defined as representative organisations of persons with disabilities that are majority-governed and led by persons with disabilities for persons with disabilities (IASC 2019, UN 2018). OPDs can vary significantly in their operational focus, geographies, and membership. In humanitarian contexts, they serve diverse roles and functions, including but not limited to providing technical guidance on disability to humanitarian organisations, removing barriers to access humanitarian assistance; collecting data, conducting needs assessments, and providing information on the location and situation of people with disabilities; delivering humanitarian assistance and support services (e.g., psychosocial support services, accessible information, in-kind assistance), advocating for the rights of people with disabilities with government stakeholders and the humanitarian architecture, including in line with the commitments of the UN Convention on the Rights of Persons with Disabilities (CRPD) (IASC 2019; IDA and Norad 2022). A 2019 study by CBM International, Humanity and Inclusion and the International Disability Alliance analysed 39 case studies on the many different ways that OPDs engage in humanitarian and recovery response (CBM, HI and IDA 2019). A 2015 study by Humanity & Inclusion found that OPDs implement conduct awareness raising on the needs of people with disabilities (71% respondents), identify persons with disabilities in crisis contexts (62% respondents), and conduct initial needs assessments of people with disabilities (53% respondents). With the significant increase in humanitarian needs over the past decade, further data is currently needed to confirm patterns in humanitarian response and in turn inform more tailored support to these organisations.

Progress has been made over the past decade in recognising the need to include inclusion of people with disabilities and their representative organisations in humanitarian frameworks and policies (Box 1). The 2016 World Humanitarian Summit was a key turning point for the institutionalisation of disability inclusion in the humanitarian sector, leading to the adoption of the Charter on Inclusion of Persons with Disabilities and the system-wide IASC Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action (Lange 2020). The strengthening of commitments to meaningfully engage people with disabilities and their representative organisations contribute to progress on other priorities in the humanitarian sector, including accountability to affected people and the localisation agendas.

To complement this initial momentum, additional efforts are currently required to

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ensure that commitments and guidelines are systematically translated into action.

Emerging evidence shows that participation of persons with disabilities, through their representative organisations, is increasing (IDA 2022). However, participation of OPDs in the humanitarian sector remains limited and unequal across the diverse constituencies of the disability rights movement (IDA 2022). In addition, there are significant gaps in the evidence base on what works for disability inclusion, with limited breadth and depth of quality evidence across different areas of humanitarian action.

The key legal and policy instruments calling for the engagement of people with disabilities and OPDs in humanitarian action include the following:

[Convention of the Rights of Persons with Disabilities](#) (CRPD) (2006)

- Article 4.3 of the CRPD calls on States Parties to engage with persons with disabilities through their representative organisations.
- Article 11 requires State Parties to take all necessary measures to ensure the protection and safety of persons with disability in situations of risk, including armed conflicts, humanitarian emergencies, and natural hazards.
- General Comment 7 clarifies the defining characteristics of OPDs and provides guidance on how to effectively ensure the participation of OPDs in CRPD implementation and monitoring.

[Security Council Resolution 2475](#) (2019)

- Calls upon Member States and parties to armed conflict to protect persons with disabilities in conflict situations, ensure they have access to justice, basic services and humanitarian assistance, and enable their meaningful participation in humanitarian action, including through their representative organisations.

[Sustainable Development Goals](#) (2015)

- Emphasises a commitment strives to leaving no one behind, and sets out the responsibility of states to respect, protect and promote human rights without discrimination of any kind, including in relation to persons with disabilities.

[Charter on Inclusion of Persons with Disabilities in Humanitarian Action](#) (2016)

- Calls on signatories to promote the meaningful involvement of persons with disabilities and their representative organizations in the needs assessment, design, implementation, coordination, monitoring and evaluation of humanitarian preparedness and response programs and draw from their leadership, skills, experience, and other capabilities to ensure their active participation in decision making and planning processes including in appropriate coordination mechanisms.

[Sendai Framework for Disaster Risk Reduction 2015-2030](#)

- Recognises that persons with disabilities and their organizations are critical in the assessment of disaster risk and in designing and implementing plans tailored to specific requirements, taking into consideration, inter alia, the principles of universal design.

[FCDO Disability Inclusion and Rights Strategy 2022-2030](#)

- Outlines FCDO's commitment to disability inclusion across priority intervention areas, including humanitarian action. It also communicates a commitment to strengthening delivery, leadership and decision-making by OPDs.

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3. Methodology

This evidence review has been developed through the [Disability Inclusive Development \(DID\) Helpdesk](#), a research and advice service for FCDO and other UK government departments that provides evidence-based support on disability inclusion in policy and programming.

The report was guided by the following questions, co-created with the research enquirer:

- What is the evidence on how OPDs are responding to meet the needs of persons with disabilities in humanitarian crises? What types of support do OPDs require to do so? What challenges do they face?
- What are the mechanisms and ways to reach OPDs (both within UN humanitarian system, and via civil society), including good practice approaches? What are the challenges and limitations?
- What are the barriers to OPDs and persons with disabilities participating in/having influence over humanitarian decision-making, and any good practice in addressing these?

These questions were explored through both primary and secondary data collection.

In the first instance, a rapid document review was conducted to understand the evidence on OPD engagement in humanitarian action and decision-making and identify good practice approaches for funding mechanisms and partnerships between OPDs and humanitarian actors. Relevant publications were sourced through online searches and signposting to relevant resources by research participants. Open-source publications with a global or regional scope were prioritised for this evidence review.

Secondary data was complemented by consultations with seven key informants. Six individuals were consulted through semi-structured interviews, including five representatives of OPDs/disability-led organisations¹ and one member of the UN Disability Advisory Group. One OPD representative contributed through written inputs. Participants consulted as part of this research represented a diverse group of OPDs/disability-led organisations, in terms of size, geography, operational focus and types of impairment represented. It included the perspectives of individuals operating in acute and protracted crises resulting from a range of different causes (e.g., armed conflict, climate-related disaster, health emergency). The findings were discussed with participants through a validation session, which informed the final set of recommendations.

There were a number of limitations to this research, resulting from time constraints and the rapid nature of this query. Due to rapid nature of this research, it was not possible to comprehensively review all relevant publications. Similarly, it was not possible to conduct a comprehensive co-creation process with OPDs, as good practice would suggest. We recommend that this research and guidance is validated through consultation with a wider range of OPDs. The research was guided by an intersectional approach, aiming to engage and capture the perspectives of a wide range of OPDs, including those representing individuals facing higher barriers to meaningful participation (e.g., women and gender-

¹ Research participants had varying preferences on adopting person-first language (organisation of persons with disabilities) or identity-first language (disability-led organisation) when referring to their organisations. To reflect these preferences as well as the language most commonly used in the literature and by FCDO, the evidence review will refer to OPDs when discussing the general evidence and use both terminologies and/or use the term 'research participants' more broadly when discussing evidence from consultations.

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diverse people with disabilities, older persons, children, people with psychosocial disabilities, autistic people, people who are deaf-blind or people with intellectual disabilities). However, due to the timeline of the research and availability of respondents, most OPDs engaged in consultations represented a broad membership base. A list of experts consulted is included at the end of the report.

4. How OPDs are responding to meet the needs of persons with disabilities in humanitarian crises

The available evidence suggests that OPDs hold wide-ranging roles across the spectrum of humanitarian action, from preparedness to response and recovery. In crisis contexts, they can take on the roles of first responders, technical experts, referral mechanisms, community representatives, and advocates to ensure that their constituency is receiving access to essential information and services (CBM International, HI & IDA 2019). OPDs are also actively engaged in awareness raising and information sharing over direct service provision and can partner with humanitarian actors to provide technical support to the delivery of emergency services (Humanity & Inclusion 2015). OPDs are the best placed and uniquely equipped to know the requirements of persons with disabilities whom they represent and how to reach them (IDA & Norad 2022). Under the UN CRPD, states have a legal obligation to “closely consult with and actively involve” persons with disabilities through their representative organizations (UN 2006; UN 2018).

OPDs consulted as part of this evidence review provided diverse examples of engagement in humanitarian preparedness and response, including:

- Providing counselling and psychological support to people with disabilities during crises.
- Acting as conduits to connect people with disabilities with accessible evacuation and other services.
- Securing and delivering humanitarian assistance, including food, non-food items such as hygiene kits, and assistive devices.
- Advocating with national authorities and humanitarian actors for the rights of people with disabilities in emergency contexts.

Despite this, it is important to note that not all OPDs have a mandate specifically linked to humanitarian action. In many cases, at the onset of humanitarian emergencies, OPDs will not have previously engaged with the humanitarian sector and its coordination and funding mechanisms, nor partnered with traditional humanitarian actors (IASC 2019). A global survey conducted by Humanity and Inclusion (2015) found that 81% of the OPDs surveyed reported having continued to run their activities during the crisis, with 36% respondents adapting their existing activities to respond to the evolving needs of their constituency and 29% developing new activities in response to the crisis.

Case studies: OPDs participating in humanitarian response and recovery:

In 2019, CBM Global, IDA, and Humanity & Inclusion published a collection of case studies, which illustrate the diverse ways in which OPDs have participated in humanitarian response and recovery. Examples include:

- In 2014, the Lebanese Association for Self-Advocacy (LASA), a national OPD led by and

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for persons with intellectual disabilities, ran monthly information and discussion sessions targeted towards refugees with intellectual disabilities and their families.

- In the aftermath of the 2015 earthquake in Nepal, the Nepal Disabled Women Association (NDWA) worked to UN Women to gather information on affected persons with disabilities and responded to their needs through the provision of humanitarian items and temporary shelter.
- During recovery from the Nepal earthquake, the National Federation of the Disabled, Nepal (NFDN) conducted training on disability-inclusive emergency shelter and settlement in emergencies for a range of different stakeholders including humanitarian actors, district and municipal officials, and representatives from the police, army, and media.

Challenges faced by OPDs in engaging in humanitarian action

The main challenges that OPDs face in engaging in humanitarian action, as evidenced by the literature and consultations include:

- **Funding and resources for OPDs and disability inclusion** – The 2020 IDA Global Survey on OPD Participation suggests that the momentum towards greater involvement of OPDs is translating into increased financial resources being directed to them (IDA 2020). Despite these positive trends, disability-led organisations remain largely under resourced. This often leads to OPDs having to concentrate their capacities on fundraising, which can take significant staff time and which often requires specific expertise. OPDs may also feel compelled to undertake projects that are based on a donor's programmatic priorities, which limits their autonomy to respond to the needs of their constituencies and ability to operate with independence and adequate capacity (IDA 2022). Increasing funding for OPDs requires donors to revise their grant-making and implementation processes to better target and support OPDs (see section 4 on funding mechanisms) (CBM 2022).
- **Organisational and technical capacity of OPDs** – As many OPDs may not have previous experiences of engaging with the humanitarian infrastructure and programme cycle, supporting these organisations to become more familiar with humanitarian systems and processes can support OPDs in bringing their disability expertise to key decision-making tables (UNICEF n.d.). It is good practice for capacity strengthening to be tailored to the local context where OPDs operate and informed by a needs assessment and the self-identified capacity gaps of OPDs. The Pacific Disability Forum, supported by funding from CBM Australia, is supporting OPDs across the region through training and mentoring aiming at improving their knowledge of humanitarian structures and their confidence to participate in these forums (Bula, Morgan and Thomson 2020).
- **Lack of accessibility and other structural humanitarian sector barriers** – The evidence emphasises the need to ensure accessibility of humanitarian response coordination mechanisms, for example by ensuring meeting spaces are physically accessible and that online meetings provide sign language interpretation, captioning, or other accommodations, in consultation with persons with disabilities. It is also necessary to strengthen the capacity and understanding among humanitarian actors regarding disability rights (e.g., non-discrimination, accessibility, reasonable accommodations, and meaningful participation), accessible communication and information, and the necessity of recognising and building OPD leadership. Humanitarian response is often managed by

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humanitarian surge teams, which have a limited understanding of local contexts and lack trusted partnerships with local disability movements (UNICEF 2021). In addition, there is a lack of knowledge among many in the humanitarian community around the defining characteristics of OPDs, which can lead to funding being channelled into organisations that are not OPDs. OPDs are a specific type of civil society organisation and should be distinguished from organisations for persons with disabilities, which have thematic experience working on disability but are not majority-led and governed by people with disabilities (IDA and Norad 2022).

Case study: Supporting OPDs technical capacity in humanitarian action

The Disability Reference Group on Inclusion of Persons with Disabilities in Humanitarian Action (DRG), currently co-chaired by the International Disability Alliance (IDA), UNICEF, and CBM Global, received funding from USAID to implement the project 'Capacity building of OPDs - strengthening disability-inclusive humanitarian action'.

The project aims to support the meaningful participation of OPDs in humanitarian action through the following activities:

- OPD Fellowships – funding OPD representatives to build their capacity as disability activists and support the DRG in strengthening linkages between the humanitarian sector and the disability movement, and contextualising learning and training materials to regional contexts.
- Orientation and awareness sessions – comprising two multilingual sessions in each of the six focus regions, focusing on introducing humanitarian frameworks and understanding OPD entry points to humanitarian action. The information included in the session included an introduction to IASC guidelines and the Humanitarian cluster system and Humanitarian Programme Cycle (HPC).
- In-person training – delivering BRIDGE CRPD training, which focuses on supporting both humanitarian actors and OPDs to better understand the CRPD and how use this knowledge to advocate for policy reform.
- Learning materials – working to develop resources with OPDs to increase the capacity of their members to engage in humanitarian processes.

5. Ways and mechanisms to reach OPDs

A key prerequisite for engaging OPDs in humanitarian contexts is having a clear understanding of the defining characteristics of an OPD, and how to reach and adequately support these organisations in crisis contexts. The UNCRPD defines OPDs as organisations that are governed, led and directed by persons with disabilities, and are comprised by a majority of persons with disabilities. As such, they should be distinguished from organisations that more generally conduct work in the area of disability. It is important to ensure that OPDs engaged are representative of different constituencies and to fill any gaps through further outreach and engagement, for example by seeking out women-led OPDs and organisations that represent different types of impairment.

Engaging with central and local governments is necessary to ensure alignment with national disability strategies and policies. Engaging, influencing, and leveraging governments can contribute to strengthening local capacities for disability inclusion and

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building lasting legacies for the inclusion of OPDs in decision-making structures.

There are a range of different avenues through which regional, national, and local OPDs can be identified, and they include:

- The [Reference Group on Inclusion of Persons with Disabilities in Humanitarian Action](#) includes membership from a large number of OPDs operating in the area of humanitarian response and at the intersection between development and humanitarian action.
- **Global, Regional or National Umbrella OPDs** – Contacting regional or national OPD networks can be a good starting point for identifying disability-led organisations with diverse operational and geographical expertise. The International Disability Alliance (IDA) [website](#) hosts links to eight global and six regional member OPDs.
- **Humanitarian Clusters System**– In protracted humanitarian emergencies, OPDs may be embedded in national humanitarian response structures, including cluster systems. There is no standardised mechanism for ensuring the participation and leadership of OPDs, and the degree of engagement of OPDs in these structures varies significantly across different contexts, as confirmed by consultations conducted with OPDs as part of this research.
- **Thematic working groups** – Age and Disability Working Groups, Disability Working Groups and Inclusion Working Groups have formed in various emergency contexts. They are commonly organised under the Protection Cluster and linked to the Humanitarian Programme Cycle and Cluster System and constitute platforms to share lessons learned between OPDs and other stakeholders working on disability.
- **Contact Lists and OPD Mapping** – Disability stakeholders (e.g., persons with disabilities, government disability focal points, disability service providers, and disability-focused NGOs) may have contact lists and/or a mapping of OPDs working in a specific area (UNICEF n.d.). For instance, the UN Office for Disaster Risk Reduction (UNDRR) has a comprehensive disability mailing list.

It is important to note that national or umbrella OPDs are not necessarily representative of all people with disabilities. For example, existing power dynamics in societies may lead to women or LGBTQI+ people with disabilities being excluded. People with impairments who face more exclusion in society, for example, people with intellectual disabilities, people with psychosocial disabilities, or people who are deaf or are deafblind, are also often less represented in umbrella organisations. When engaging OPDs, it is good practice to understand who they are representing and who may be excluded from their membership base (paying specific attention to impairment groups that are commonly marginalised, such as persons with intellectual disabilities, persons with psychosocial disabilities, and persons who are deaf and who are deafblind) and look to fill any gaps in representation through further outreach.

Emerging good practice and challenges for engaging with OPDs

Humanitarian actors can face some challenges when seeking to engage OPDs through these different avenues. In some humanitarian contexts, formal OPDs may not exist, with people with disabilities participating in or represented by community or local initiatives or having no representative group. Where formal OPDs do exist, they may have been significantly weakened by the crisis with staff themselves directly impacted by events

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and in need of urgent humanitarian assistance, or if communications lines have been affected. In mass displacement conditions, OPD members may experience difficulties in organising themselves to support humanitarian response (UNICEF n.d.).

OPDs also report challenges in accessing indirect and direct funding. Some OPDs have not had previous experience in responding to emergency situations or engaging with international and national humanitarian actors and therefore may require additional support to engage with humanitarian structures. Research participants reported finding out about funding opportunities from different sources, including international and national CSO partners, in particular larger humanitarian organisations, disability umbrella organisations, and direct outreach from donors (especially where a pre-existing partnership is in place). More research is needed to assess the extent to which these approaches to sharing information are effectively capturing available funding opportunities. Additional research should also be undertaken to assess the accessibility of existing online platforms used by donors to publish opportunities.

- **One approach could be to introduce a minimum percentage of programme funding to allocate to disability inclusion.** The reviewed evidence suggests that there is no standard percentage that is applicable across all activities and contexts (UNICEF n.d.). The [UNICEF disability inclusive humanitarian toolkit](#) proposes using the following activity-based estimates: 1-3% of the total construction cost for accessibility of the built environment; 3-4% for non-food items and basic assistive devices; or 3-7% of programme total budget for all disability-inclusion measures. Similarly, Light for the World recommends that projects allocate 2-7% of their total budget for disability inclusion (Light for the World 2017).
- **Significantly, there were very few examples of effective funding partnerships experienced or witnessed by participants involved in this research.** The structure and requirements of funding opportunities frequently make these resources inaccessible to OPDs (IDA & Norad 2022). Applications tend to be complex and time-consuming, making it difficult for smaller organisations with limited or no dedicated fundraising staff and experience in these types of applications to compete for funding. Research participants also reported that traditional eligibility requirements, such as a history of audits, and extensive due diligence, often prevent OPDs from directly receiving support from foreign government donors and UN agencies. These barriers frequently lead to larger organisations working on disability obtaining funding over organisations that are majority governed and led by people with disabilities. In some cases, larger organisations then sub-contract OPDs to support with the implementation of programmes. This can mean that OPDs receive small amounts of funding and may be limited to the priorities set by other organisations. Funding is frequently provided for specific activities, with limited resources available to cover the administrative costs required to sustain organisations and their operations. In addition, these arrangements frequently limit relationship-building between OPDs and donors.

Emerging recommendations from KIIIs for improving the accessibility and effectiveness of funding to OPDs include:

- **Build pre-existing partnerships between humanitarian actors and OPDs** through adequate resourcing and coordination – research suggests this increases the efficiencies of disability-inclusive humanitarian responses when crises strike (CBM, HI & IDA 2019). Building these networks constitutes a key component of humanitarian preparedness. This

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process requires humanitarian actors to develop an understanding of who would be best placed to establish and maintain these relationships. Additional guidance on meaningful partnerships with OPDs can be found in the FCDO Programme operating framework (PrOF) guide: Engagement & consultation with organisations of persons with disabilities.

- **Improve accessibility of funding applications** – This includes ensuring that funding opportunities are being published on accessible platforms and are widely shared. All relevant information must be in plain language, accessible for screen readers, with available translation in local languages.
- **Streamline funding requirements** – In the context of developing donor approaches to localisation, it is important to ensure that an inclusive approach is taken to understanding and addressing the specific challenges and barriers OPDs face in due diligence requirements and eligibility criteria.
- **Provide flexible funding** – There is evidence across the humanitarian sector that flexible-funding supports efficiencies and better outcomes (International Rescue Committee 2020). Flexible funding models are compatible with fragile and volatile contexts, where rapid deployment of resources may be needed at short notice and where situations and assistance change rapidly. At the same time, flexibility in funding structures allows donors to design activities on the basis of participatory needs assessments and the self-identified priorities of OPDs and their constituencies. Available funding should cover both programme activities and overhead costs, to support the administrative costs and capacity-strengthening needs of OPDs.
- **Provide long-term funding** – Long term funding helps to alleviate the resource burden experienced by OPDs, ensures continuity and effectiveness of OPD activities, and preserves the capacities of these organisations that would have otherwise have to be directed towards fundraising.
- **Provide direct funding to OPDs** – Most current models of humanitarian funding involve OPDs receiving subgrants through larger humanitarian organisations, as noted above. Direct funding to OPDs, including to larger or umbrella OPDs to support smaller organisations, can be more effective and rights-respecting, by giving OPDs the opportunity to identify the most urgent needs of their communities and have more resources to implement priority programming. However, umbrella organisations are not necessarily representative of all groups; programming should actively prioritise non-discrimination, equity and inclusion, particularly of those most likely to be marginalized.

Case studies: OPD-directed, flexible funding models

The [Global Alliance for Disaster Resource Acceleration](#) (GADRA) matches donor resources with disability-led organisations providing humanitarian relief to their communities.

Through its [Virtual Emergency Operations Centre](#), GADRA provides emergency support tailored to the self-identified needs of OPDs and empowers local OPDs to develop the capacities to implement humanitarian relief operations and improve their preparedness for future response operations. In the aftermath of the earthquake in Türkiye and Syria, GADRA is supporting [seven OPDs](#) to deliver medical equipment, support disability related living needs, and provide accessible transportation, temporary shelters, and permanent housing. The funding is also supporting organisations' themselves to re-establish safe working locations and cover their organisational and administration costs.

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At the onset of the war in Ukraine, the [Disability Rights Fund](#) (DRF) and Purposeful joined efforts to rapidly deploy resources to OPDs, with a focus on disabled activists and disabled women-led groups. The DRF contributed institutional knowledge of OPDs in Ukraine and channelled funding through Purposeful. Purposeful operates to serve girls and young activists who are traditionally marginalised from philanthropic processes and as such is accustomed to moving beyond traditional grant application procedures to mobilise resources through non-traditional financial systems to reach unregistered groups operating in crisis context. This resulted in direct funding reaching eight OPDs in Ukraine (Bokoff and Bransky 2022).

6. Barriers and good practices for the participation of OPDs in humanitarian decision-making

In line with the UN CRPD, persons with disabilities are entitled to have decision-making authority in the humanitarian decisions that affect them. In addition, the inclusion people with disabilities and their representative organisations can lead to more effective outcomes and help avoid potential harm as they bring expert knowledge on disability, which is necessary to improve the effectiveness and accountability of humanitarian operations (IASC 2019). For instance, a report by Inclusive Futures on the engagement of OPDs in the COVID-19 response found that “instead of being invited to work with governments and humanitarian actors in disaster and response planning, many OPDs found themselves trying to mitigate the consequences of policy decisions that had not adequately considered people with disabilities” (Inclusive Futures 2021).

This leadership role is recognised by OPDs, with a 2015 Humanity and Inclusion survey finding that 70% of OPDs surveyed highlighted their engagement at decision-making levels as necessary to convey the needs of people with disabilities in humanitarian response (Humanity & Inclusion 2015).

Despite these entitlements and benefits for programming, there is limited evidence of the systematic and meaningful engagement of OPDs in humanitarian decision-making by governments, funding agencies, and other key humanitarian stakeholders. The IDA-led 2020 Global Survey of OPDs in Development Programmes and Policies found that just 18.5% OPDs consulted indicated being involved in disaster risk reduction and humanitarian action by governments, 23% by the UN, and 15% by funding agencies (IDA 2020).

Findings from interviews and the literature suggest that when OPDs are consulted, it is primarily or exclusively on disability-specific issues (e.g., disability laws and policies) rather than mainstreaming across the humanitarian sector (IDA and Norad 2022). There is more limited evidence on the engagement of OPDs to support disability mainstreaming across the humanitarian sector more broadly. In addition, consultations frequently occur on an individual basis or in disability-focused consultative bodies (e.g., disability working groups), and less so within broader system-wide structures, further hindering progress on mainstreaming disability as a cross-cutting issue. OPDs/disability-led organisations consulted as part of this research described their ongoing efforts to advocate for meetings with government, donors, UN agencies, and for participation in humanitarian structures, emphasising that more progress is needed in this direction. Nevertheless, ongoing accessibility barriers to participation were reported in KII, especially in relation to engagement with national governments.

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When invited to contribute to programmes, OPDs are frequently tasked with specific activities (e.g., outreach, awareness raising) but more rarely engaged as partners throughout the planning, design, implementation, and evaluation of humanitarian interventions. Meaningful engagement requires donors and implementers to go beyond individual activities to engage OPDs as equal partners throughout the implementation of programmes.

Several participants noted that existing fora for consultation can be inaccessible to people with different types of impairment, for example for those who require sign language interpretation, captioning, or have physical accessibility needs. It is incumbent on those organising consultative mechanisms to address barriers in the physical environment, information and communications, and attitudes and knowledge, however this is rarely done in practice (IDA 2022).

Expert contributors

Marcie Roth, Executive Director and Chief Executive Officer, World Institute on Disability (WID), global OPD

Moaffak Alkhafaji, Head of the Iraqi Alliance of Disability (IADO)

Technical expert, national women-led OPD²

Technical expert, Disability Advisory Group

Technical expert, national OPD

Technical expert, national OPD

Technical expert, regional OPD

² Some expert contributors to this report preferred to remain anonymous.

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About Helpdesk reports: The Disability Inclusion Helpdesk is funded by the UK Foreign, Commonwealth and Development Office (FCDO), contracted through the Disability Inclusion Team (DIT) under the Disability Inclusive Development Programme. Helpdesk reports are based on between 4 and 5 days of desk-based research per query and are designed to provide a brief overview of the key issues and expert thinking on issues around disability inclusion. Where referring to documented evidence, Helpdesk teams will seek to understand the methodologies used to generate evidence and will summarise this in Helpdesk outputs, noting any concerns with the robustness of the evidence being presented. For some Helpdesk services, in particular the practical know-how queries, the emphasis will be focused far less on academic validity of evidence and more on the validity of first-hand experience among people with disabilities and practitioners delivering and monitoring programmes on the ground. All sources will be clearly referenced.

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Suggested citation:

Miglio, V. and Buchanan, J. (2024) *Engaging organisations of persons with disabilities in humanitarian crises*, Disability Inclusion Helpdesk Research Report No. 116. London, UK: Disability Inclusion Helpdesk.