



Lessons learned

Executive summary

Mechanisms for coordination of disability inclusion in Humanitarian Action:

A Comparative Case Study Examination of Experiences in Afghanistan, Ukraine, Democratic Republic of the Congo, Bangladesh and Venezuela

Protection and Risk Reduction Division
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Cover Image

The will of these women to rebuild their lives is a great source of hope. Collective exercises session at Sarthe Hospital, Haiti.

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Executive summary

As we strive towards a more inclusive global humanitarian system, it becomes increasingly apparent that the needs and rights of persons with disabilities often go unaddressed. This is a consequence of critical challenges such as the scarcity of disability disaggregated data for needs assessments, lack of accessible accountability mechanisms, coordination issues, and the pressing need for capacity building – especially targeted at local actors and Organizations of Persons with Disabilities (OPDs) – which further compounds the issue. It is therefore vital to explore and implement more strategic approaches to address these challenges towards building a humanitarian architecture that seamlessly includes persons with disabilities through more inclusive coordination structures.

In 2019, the Inter-Agency Standing Committee (IASC) published its guidelines for including persons with disabilities in all aspects of humanitarian response, based on the principles outlined in the Convention on the Rights of Persons with Disabilities. While the guidelines brought a proactive orientation to disability inclusion, the guidelines were actually less explicit on the operational aspects, such as how to establish clear accountability structures and keep them on track. Recommendations were made to include disability Focal Points as well as Organizations of Persons with Disabilities (OPDs) in inter-cluster meetings, and to invest in capacity building initiatives for coordination mechanisms. However, the IASC guidelines lacked clear directives on how a coordinating mechanism to oversee disability inclusion across different sectors would work, or what it would look like. Hence the need for more in-depth analysis about what experiences have been tried and what the main value-add has resulted.


Using a case study approach, we considered five humanitarian situations, focusing on exploring various models of coordination mechanisms for disability inclusion in humanitarian action, with an intent to identify what makes these structures work and drives more disability-inclusive humanitarian programming.

Our methodological approach to developing the case studies consisted of a three-step process:


1. An initial mapping of existing mechanisms for the coordination of disability inclusion sampling all situations with Humanitarian Response Plans (HRPs) in 2022;
2. Identifying the five most instructive cases based on feedback and input provided by a Technical Task Force (TTF)¹; and
3. Carrying out a more in-depth analysis of the chosen five cases.

1 The technical task force was established as part of the project “From Guidelines to Action”. The role of this TTF was to input and provide feedback on the methodology for the initial mapping and later the comparative case studies on mechanisms for coordination on disability inclusion. This included the selection of the case studies. Members in the Technical Task Force include: Ricardo Pla Cordero (UNHCR), Randa Hassan (UNOCHA), Isabelle De Muyser (UNOCHA), Kirsten Lange (UNICEF), Aline Carruet (WFP), Vivian Alt (IOM), Pauline Thivillier (IRC), Gordon Rattray (EDF), Milica Nikolic (WHH), Sabreen Al Dweib (HI – GPC), Irene Mulunda (HI) and Ulrike Last (HI).

The initial mapping revealed evidence of some form of disability-related coordination mechanism in 18 out of 28 sampled countries. Detailed information was further obtained through follow-up interviews with key informants. In these interviews, no evidence was found suggesting the systematic use of disability inclusion focal points at the agency level or within coordination structures. To determine which examples were worthy of deeper study, four key criteria were used, including the richness of information available, the diversity of mechanisms, target group suitability, and the number and quality of outcomes achieved by the coordination mechanism. This process led to the selection of five case studies for further examination², providing valuable insights into how the coordination of disability inclusion occurred in various humanitarian contexts in 2022 and 2023:

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1. In **Afghanistan**, the establishment of the Disability Inclusion Working Group (DIWG) in 2021 under the Inter-Cluster Coordination Group hosted by OCHA represented a significant step towards integrating disability considerations in the country's complex humanitarian crisis. The establishment of the DIWG was recommended in the 2021 HRP. It has been coordinated by Humanity & Inclusion with two co-chairs from the United Nations and one from civil society. Notably, the 2023 Humanitarian Response Plan includes a budget line-item for the cost of the coordination group, reflecting the seriousness of commitment to this issue. Humanity & Inclusion played a pivotal role in this development, alongside other partners, and subsequently an organization of persons with disabilities (OPD) has been elected as a co-lead of the working group.

The case study highlighted the vital role of a full-time coordinator and sustainable funding in ensuring the effectiveness of disability inclusion coordination. The DIWG was instrumental in transforming disability inclusion from an afterthought to a central component of the humanitarian response. The Group's work demonstrates the tangible improvements in coordination and resource allocation that can be achieved when disability inclusion is systematically integrated.

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2. In **Bangladesh**, following the sudden influx of over seven hundred thousand refugees into Bangladesh's Cox's Bazar district in 2017, four local and international NGOs decided to coordinate the work around promoting a disability and age-inclusive response via advocacy, capacity development and technical support and enhancing data around persons with disabilities and elderly persons. In 2018, these four NGOs established an Age and Disability Working Group (ADWG) involving a diverse membership of humanitarian actors, including OPDs, local NGOs and Sector representatives. Engagement of OPDs as members in the ADWG highlights what future working arrangements could look like.

The ADWG has experienced different phases of formalization and restructuring that continue to the present moment. At the time of the case study visit, the ADWG continued to be associated with the UNHCR-led Protection Sector, with discussion underway to integrate the mechanism formally into the Inter-Sector Coordination Group as a cross-cutting issue.

Considering the ADWG, it became clear that much can be achieved through co-leadership with regards to capacity development, better data, advocacy and technical support, despite the varying funding levels of the different

² Four of the case studies were carried out virtually by the consultant Stephen Perry, a fifth (Bangladesh) was facilitated by an in-person visit by Ulrike Last.

partners. The leadership of a fully-funded coordinator since 2022 has been instrumental. At the same time, stronger leadership from the UN is required if disability- (and age-) inclusion is to be more prominently considered in the Joint Response Plan for Cox's Bazar, the Multi-Sector Needs Assessment process, as well as the sectorial response planning and monitoring.

3. In **Ukraine**, the Age and Disability Technical Working Group (ADTWG) was created in 2014 under the UNHCR-led Protection Cluster to facilitate a response to the unique needs presented by the country's population of elderly persons following the Donbas/Crimea crisis that year. The ADTWG has been led by HelpAge International since its inception. In 2021 there was discussion about deactivating the Protection Cluster (and the ADTWG) given the shape of the conflict at that time, but with the full-scale Russian invasion in 2022 that led to massive internal displacement and a refugee crisis, the ADTWG faces new challenges and a shift in its operational approach. It is grappling with key disability-related issues, such as continuing to provide referral services to persons with disabilities who have been displaced into unfamiliar areas of Ukraine with no support network, while at the same time trying to be more technical in its support of the Humanitarian Program Cycle (HPC) processes.



The experience in Ukraine shows the importance of context-specific approaches and strategic engagement in broader policy reform. The case further illustrated the importance of an issue platform to advance crucial advocacy work, particularly around pension reform, showcasing the possibility of achieving substantial policy changes that directly benefit people with disabilities.

4. The East Eagle Foundation's (EEF) work in the **Democratic Republic of the Congo** exemplifies a localized, grassroots mechanism to coordinate the work of local OPDs in relation to disability inclusion specifically related to education. At the time of the case study, the EEF was unaffiliated with any UN-led humanitarian coordination mechanism, although it had an interest in finding a suitable entry-point, such as the UNICEF and Save the Children led Education Cluster.



By coordinating its network of small OPDs across the country, the EEF has been facilitating localized responses to the needs of persons with disabilities. However, this model is confronted with an "expectation discrepancy", as these OPDs lack understanding of the Humanitarian Programme Cycle (HPC) and international funding mechanisms, while the UN and other international actors may not fully grasp the capabilities and potential contributions of these local entities or have the tools to appropriately engage with them.

In the Democratic Republic of Congo, the interconnected network of OPDs underscores the importance of collaboration and resource sharing. Many of the OPDs in the EEF are engaged in humanitarian action in inclusive education and are keenly interested in being more formally linked to the coordination system. Despite facing logistical and funding challenges, the decentralized and participatory approach to service delivery created by this network has proven effective, particularly in contexts where OPDs are resource-constrained and operate on a volunteer basis.



5. In **Venezuela**, the *Grupo de Trabajo sobre Edad y Discapacidad en la Acción Humanitaria* (GTEDAH) was established by the UNHCR-led Protection Cluster in 2020 recognizing the opportunity to advance protection mainstreaming principles in a situation strained by political turmoil, international sanctions, and the collapse of social services. The complexity of international organizations complying with Venezuelan registration requirements has necessitated a consortium approach. CONSORVEN and Convite are the co-leads of the GTEDAH³. CONSORVEN and Convite approached HelpAge and Humanity & Inclusion to support their adaptation to work in the humanitarian coordination space. This alliance offers a short-term solution to addressing the coordination of age and disability issues amidst the country's current situation in a context where local organizations are keen to participate in humanitarian action. The humanitarian architecture in Venezuela has promoted consortia of international organizations with local organizations with the explicit aim to strengthen these local organizations. Over time this approach has proven effective with many local organizations building capacity and becoming in-turn mentors to other local organizations.

The case of Venezuela revealed how awareness-raising and advocacy about disability inclusion can change attitudes within implementing agencies and contribute to stronger, more inclusive humanitarian assistance. The working group has managed to secure programmatic changes that directly benefited individuals with disabilities such as improvements to local pool-funded projects.

Each of the five case studies present a compelling case for the importance of coordinating disability inclusion in humanitarian responses. The lessons from Afghanistan, Bangladesh, Ukraine, DRC, and Venezuela underscore the transformative potential that exists to amplify the voices of individuals with disabilities, but also to enhance the overall effectiveness of humanitarian interventions. In four of the five cases (Venezuela, Afghanistan, Ukraine and Bangladesh) disability inclusion was integrated more completely in the Humanitarian Program Cycle and response plan.

The five case studies have common features: all five struggle to finance the crucial work of coordination, whether they are on a shoe-string budget or no budget at all. Each of the mechanisms reviewed here required additional support from UN agencies and governmental coordination structures to gain a seat at the table to bring the perspective of persons with disability into decisions related to the delivery of humanitarian assistance. The current UN-led humanitarian organizational architecture does not recognize disability inclusion as a cross-cutting theme in the same manner as Gender, Accountability to Affected Populations (AAP) or Protection from Sexual Exploitation and Abuse (PSEA) all of which have mandatory trainings and codes of conduct that all UN staff, partners and other personnel must adhere.

These case studies also illustrate that when progress is made to engage with UN-led coordination structures, it is usually the result of an individual within the formal humanitarian system taking the agenda forward.

³ [CONSORVEN](#), the Confederación Sordos de Venezuela which works with Deaf persons, and [Convite](#), an organization focused on training vulnerable groups such as women, young people and older adults.

Several of the mechanisms have developed tools to promote awareness raising amongst humanitarian colleagues, but no global framework exists to share these resources between situations. The need for improved disability data is recognized widely by humanitarian actors, and examples of one-off successes are illustrated here, but no systematic entry-point has been found to support the large-scale needs assessment processes that occur around many situations nor any support to the monitoring of disability inclusion in humanitarian programming. Some contribution to sector standards is emerging to varying extents but no common tools to facilitate this exist. Each of the coordination mechanisms do raise their voice to advocate for filling the gaps with varying success given their limited resources and marginal positions.

As a key takeaway, readers should understand that these coordination mechanisms for disability inclusion are not merely a matter of “good practice” but rather were seen as a critical determinant in realizing truly inclusive, equitable, and efficient humanitarian responses in these cases. While a free-standing coordination mechanism may not be necessary to integrate disability inclusion, concerted attention was sustained in the cases where they were in place.

Drawing inspiration from the experience of how gender has been increasingly mainstreamed into humanitarian action, in the case of gender it followed a long-term process facilitated by a series of reforms backed up with technical and political support. Mainstreaming gender required more systematic production of gender-disaggregated data. Participation expectations needed to change over time so that women’s voices could be better represented in decision-making situations. More attention needed to be paid to gender across sectors and clusters through results frameworks and monitoring indicators. All this was made possible with sustained training and technical support. While the system may not have arrived yet at full gender equality, a lot of progress has been made over the past decades.

It might be the wrong lesson to draw that dedicated coordination mechanisms for disability inclusion are a necessary permanent feature of the humanitarian architecture. Where these mechanisms could be useful over the short- and medium-term as seen in these case studies is to provide organizational space for the coordination of disability inclusion in the humanitarian response across sectors and clusters. Disability inclusion focal points is something assumed by the Guidelines for the Inclusion of Persons with Disabilities in Humanitarian Action as a recommended approach to integrate disability into coordination, but was something that was not observed as a common practice in these case studies. Placing a disability focal point within the Humanitarian Team or Inter-sector coordinator group or similar structure is another approach that could be assessed. Exploring why the disability inclusion focal point modality has not been more widely adopted, or what alternatives could exist to stand-alone mechanisms for the coordination of disability inclusion could be the focus of future follow-up monitoring of how disability inclusion is integrated into coordination structures.



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