



Lessons learned

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## 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

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Protection and Risk Reduction Division  
October 2023

LL 21 n°2



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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, Haïti.

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October 2023

## 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 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 they 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 drive 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<sup>1</sup>; and
3. Carrying out a more in-depth analysis of the chosen five cases.


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<sup>1</sup> The technical task force was established as part of the project “From Guidelines to Action”. The role of this technical task force 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.

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 examination<sup>2</sup>, 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 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 capacity development, advocacy, capacity development and technical support and enhancing data around persons with disabilities and older 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

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<sup>2</sup> 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 older 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 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 GTEDAH<sup>3</sup>. 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 Persons (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 more likely than not this is the result of an individual within the formal humanitarian system taking the agenda forward.

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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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## Acronyms and Specialized Terms

<b>AAP</b>	Accountability to Affected Populations
<b>ACAPS</b>	Assessment Capacities Project
<b>ADWG</b>	Age and Disability Working Group, Bangladesh
<b>ADTWG</b>	Age and Disability Technical Working Group, Ukraine
<b>AIDES</b>	Actions et Interventions pour le Développement et l'Encadrement Social, local NGO in DRC that represents civil society in the Education Cluster
<b>AOAD</b>	Accessibility Organization for Afghan Disabled
<b>AOR</b>	Area of Responsibility (under the Protection Cluster several AORs focus on different aspects of protection, for example Child Protection)
<b>Catch 22</b>	A problematic situation for which the solution is denied by a circumstance inherent in the problem; any no-win situation where the problem and its solution are reliant on each other
<b>CBM G</b>	Christoffel-Blindenmission (originally, now simply CBM) and G for Global
<b>CD</b>	Capacity development
<b>CDD</b>	Centre for Disability in Development, Bangladesh
<b>CERF</b>	Central Emergency Response Fund
<b>CONSORVEN</b>	Confederación Sordos de Venezuela (Confederation of the Deaf of Venezuela)
<b>COVID-19</b>	Coronavirus Disease 2019
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>CSO</b>	Civil Society Organization
<b>DFID SBC</b>	Department for International Development, Shared Business Case. DFID's name has now been changed to the Foreign, Commonwealth & Development Office (FCDO)
<b>DI</b>	Disability inclusion
<b>DIPGs</b>	Disability Inclusion Promotion Groups, Bangladesh
<b>DIWG</b>	Disability Inclusion Working Group, Afghanistan

## Acronyms and Specialized Terms

<b>DRC</b>	Democratic Republic of the Congo
<b>DRC</b>	expectation discrepancy - The gap between the anticipated outcome and the actual results
<b>DRG</b>	Disability Reference Group, global platform
<b>DSCs</b>	Disability Support Communities, Bangladesh
<b>ECHO</b>	European Civil Protection and Humanitarian Aid Operations
<b>EEF</b>	East Eagle Foundation,
<b>FAO</b>	Food and Agriculture Organization
<b>FP</b>	Focal point
<b>GBV</b>	Gender-based violence
<b>GenCap</b>	Gender Standby Capacity Project
<b>GL</b>	Guideline
<b>GTEDAH</b>	Grupo de Trabajo sobre Edad y Discapacidad en la Acción Humanitaria (Age and Disability Working Group in Humanitarian Action), Venezuela
<b>HCT</b>	Humanitarian Country Team
<b>HI</b>	Humanity & Inclusion
<b>HNO</b>	Humanitarian Needs Overview
<b>HPC</b>	Humanitarian Program Cycle
<b>HRP</b>	Humanitarian Response Plan
<b>IASC</b>	Inter-Agency Steering Committee
<b>IASC GL</b>	Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action (IASC, 2019)
<b>ICCT</b>	Inter-Cluster Coordination Team, Afghanistan
<b>IDP</b>	Internally Displaced Person
<b>INGO</b>	International Non-Governmental Organization
<b>IOM</b>	International Organization for Migration

## Acronyms and Specialized Terms

<b>ISCG</b>	Inter-sector coordination group, Bangladesh
<b>JRP</b>	Joint Response Plan, UNHCR
<b>LGBTQI+</b>	Lesbian, Gay, Bisexual, Transgender, Queer (or Questioning), Intersex, + symbolizing inclusivity for additional sexual orientations, gender identities, and expressions.
<b>MASHA</b>	Ministère des Affaires Sociales et de l'Action Humanitaire (Ministry of Social Affairs and Humanitarian Action, DRC)
<b>MEPS</b>	Ministère de l'Enseignement Primaire, Secondaire et Professionnel (Ministry of Primary, Secondary, and Professional Education, DRC)
<b>MSNA</b>	Multi-Sector Needs Assessment
<b>NAPD</b>	National Assembly of Persons with Disabilities, Ukraine
<b>NGO</b>	Non-Governmental Organization
<b>OCHA</b>	United Nations Office for the Coordination of Humanitarian Affairs
<b>OPDs</b>	Organizations of Persons with Disabilities
<b>PiN</b>	Persons in Need (of humanitarian assistance)
<b>PSEA</b>	Protection from Sexual Exploitation and Abuse
<b>REACH</b>	INGO, specializing in providing information management and assessment services to support evidence-based decision-making and planning in humanitarian contexts
<b>RIADIS</b>	Red Iberoamericana de Organizaciones no Gubernamentales de Personas con Discapacidad y sus Familias (Latin American Network of Organizations of Persons with Disabilities and their Families)
<b>SAD</b>	Sex, Age and Disability (disaggregated data)
<b>SBC</b>	Shared Business Case (DFID/UK terminology)
<b>TOR</b>	Terms of Reference
<b>UNCT</b>	United Nations Country Team
<b>UNDIS</b>	United Nations Disability Inclusion Strategy

## Acronyms and Specialized Terms

<b>UNFPA</b>	United Nations Fund for Population Activities
<b>UNHCR</b>	United Nations High Commissioner for Refugees
<b>UNICEF</b>	United Nations Children’s Fund
<b>USAID</b>	United States Agency for International Development
<b>WASH</b>	Water, Sanitation, and Hygiene
<b>WFP</b>	World Food Programme
<b>WG</b>	Working Group
<b>WG SS</b>	Washington Group Short Set of questions
<b>WHO</b>	World Health Organization

# Introduction

## A. Disability inclusion in humanitarian responses

The international humanitarian community has long recognized the urgent need to include persons with disabilities in their responses. Despite this, in the current architecture of the international humanitarian system, major gaps exist in terms of quality data concerning persons with disability, the coordination of humanitarian actors with respect to disability inclusion, building the capacity of actors in this area, and with the quality of programming that ensures persons with disability have access to humanitarian assistance. As humanitarian crises continue to unfold across the globe, it is crucial to address these gaps and ensure the needs and rights of persons with disabilities are no longer neglected.

Several key challenges exist that prevent persons with disabilities from being fully included in humanitarian response actions, including the poor state of disability disaggregated data to inform needs assessments and track implementation performance, the need for more accessible accountability mechanisms that also establish clear lines of responsibility, coordination across the system, and underlying all of this, the need for capacity building, paying particular attention to local actors and organizations of persons with disabilities.

Addressing these critical issues can pave the way for a more inclusive and effective humanitarian system, ultimately transforming the lives of millions of persons with disabilities in crisis-affected settings worldwide.

## B. Overview of the IASC Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action

The Inter-Agency Standing Committee Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action were first published in 2019 to provide a framework for ensuring that persons with disabilities are included in all aspects of humanitarian response. These guidelines were developed by the Inter-Agency Standing Committee (IASC), which is a collaboration of United Nations (UN) and non-UN organizations working in humanitarian response. The IASC Guidelines are based on the Convention on the Rights of Persons with Disabilities which recognizes the rights of persons with disabilities to equal participation in society, including in humanitarian action.

The Guidelines are meant as an initial proactive step towards humanitarian response for persons with disabilities and their care givers. While this guidance did comprehensively describe what needed to be done by actors in terms of programming under humanitarian clusters and information management, it was basically silent on key operational questions such as how different sector actors would be held accountable through the Humanitarian Program Cycle (HPC) to include disability inclusion issues in needs assessments, response planning, implementation and evaluation.

Two sections of the Guidelines propose what disability inclusive coordination should look like. Section 9 (“Stakeholder roles and responsibilities”) recommends that the humanitarian leadership in a response “ensure that disability focal points and/or Organizations of Persons with Disabilities



are included in inter-cluster meetings.”<sup>4</sup> Disability focal points would be a point of oversight and accountability for ensuring that disability inclusion is mainstreamed throughout all aspects of the organization’s work.

Section 10 (“What sectors need to do”) acknowledged that coordination mechanisms were “ad hoc and inconsistent” and that “disability is not yet systematically included in inter-agency coordination mechanisms” and went on to recommend several “must do” actions:

- Engage families and OPDs in coordination and needs assessment processes
- Ensuring that coordination mechanisms include OPDs in their capacity-building initiatives
- Build the capacity of coordination personnel on disability inclusion<sup>5</sup>

As a cross-cutting issue, disability inclusion relates to the work of every cluster – WASH, education, protection, etc. – but no particular mechanism to coordinate disability inclusion has been recommended although several models have emerged in different contexts, responding to local characteristics, but largely being driven by interested individuals within the system.

In principle a key value addition of disability-inclusive coordination mechanisms would be to provide a platform for persons with disabilities to participate together with focal points from across responding agencies in decision-making processes and to voice their concerns and recommendations. These mechanisms could promote the exchange of information and best practices among stakeholders, to improve the quality and effectiveness of more inclusive humanitarian programming.

Effective coordination and collaboration are essential to ensure that the needs and priorities of persons with disabilities are prioritized in all phases of humanitarian action. As the Office for the Coordination of Humanitarian Affairs OCHA describes it, coordination is “central to the effort to save lives”.<sup>6</sup>

## C. Purpose of the assignment and case study selection

The aim of the assignment is to understand more comprehensively and systematically how issues related to disability inclusion are expressed through Humanitarian Country Teams (HCTs) in emergency response settings via different forms of coordination.

The Theory of Change is that if clear examples can be documented where disability inclusive coordination mechanisms have clearly added value to a humanitarian response scenario, the momentum would build behind the IASC’s disability inclusion guidelines recommendation to establish disability coordination mechanisms.

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<sup>4</sup> IASC Task Team on Inclusion of Persons with Disabilities in Humanitarian Action, [Guidelines: Inclusion of Persons with Disabilities in Humanitarian Action](#), July 2019, p. 58

<sup>5</sup> [Ibid.](#), p. 69-70

<sup>6</sup> Office for the Coordination of Humanitarian Affairs, “Coordination to Save Lives: History and Emerging Challenges”, 2012.

## Methodology

The process to develop the case studies presented here involved three-steps: mapping what coordination mechanisms already exist, identifying the ones where the most vivid lessons are evident, and more fully exploring the selected cases.

### A. Mapping of coordination mechanisms in 2022

Humanitarian Response Plans (HRPs) were prepared in 2022 became the initial sample framework for the global mapping exercise. Northwest Syria was included as a follow-up to an earlier case study, as well as to practically ground the analysis of disability inclusion coordination mechanisms in the Syria response due to its complexity.

Mapping the coordination of disability inclusion in selected refugee responses was also attempted due to the interest in looking at how disability inclusive coordination occurs in refugee responses, where disability inclusion is also an acute issue. Three situations were considered Bangladesh, Jordan and Uganda.

The global mapping drew on several previous exercises, including preliminary assessments carried out by Humanity & Inclusion with data added by UNICEF, a survey of responses described on the platform [ReliefWeb Response](#), and OCHA's 2021 survey of coordination structures. This desk research determined that 18 of the 28 countries in the sample framework had some evidence of a disability-related coordination mechanism being in place at one point in time. In twelve of these cases, a current key informant could be identified.

**Table 1 illustrates where mechanisms for the coordination of disability inclusion were observed in the 2022 Humanitarian Program Cycle period.**

Country	No Evidence	Reported, but no current activity	Reported and reviewed in mapping
Afghanistan			X
Bangladesh (1)			X
Burundi		X	
Burkina Faso		X	
Central African Republic		X	
Cameroon	X		
Chad	X		
Colombia	X		
Democratic Republic of Congo			X

Country	No Evidence	Reported, but no current activity	Reported and reviewed in mapping
El Salvador (2)	X		
Ethiopia	X		
Guatemala (2)	X		
Honduras (2)	X		
Haiti	X		
Iraq (3)			X
Jordan (1)			X
Libya	X		
Mali	x		
Myanmar			X
Mozambique			X
Niger		X	
Nigeria	X		
occupied Palestinian territory	X		
Somalia		X	
South Sudan		X	
Sudan	X		
NW Syria			X
Uganda (1)			X
Ukraine			X
Venezuela			X
Yemen			X
	13	6	12

Notes:

(1) Refugee Coordination Model

(2) Regional humanitarian response

(3) Disability coordination mechanism identified in earlier mapping exercises is actually a United Nations Disability Inclusion Strategy task force that meets to consolidate the UN Country Team's input. It has no humanitarian function, and only coordinates UNCT answers to the UNDIS accountability framework.

Follow-up interviews were then carried out with key informants in the 12 countries with reported activities to learn more about the shape and characteristics of its disability inclusion coordination mechanism.

## B. Selection criteria for case studies

Four key criteria were proposed by the project's Technical Working Group for reviewing the coordination structures and identifying vivid cases for further study:

- Considering the richness of information and key informant that can deepen the understanding based on pre-information and support learning (good versus bad practice)
- To reflect the diversity of disability inclusion mechanisms within the humanitarian/displacement architecture
- Target group suitability, or who would be most interested in the case study when completed
- Consideration of the number and quality of results achieved by the coordination mechanism especially linked to current discussions around HPC reforms, disability inclusion, inter-sectionality, being people-centered, an example of localisation

Drawing on what was learned in the mapping exercise, five examples were proposed to the Technical Working Group for further elaboration in this study:

**Table 2 Case Studies as Proposed to the Technical Working Group**

Country	Richness of Information	Diversity of Approaches	Audience Interest	Results Achieved
<b>Ukraine</b> Age and Disability Technical Working Group	Current full-time Coordinator (HelpAge), past Coordinator, disability technical advisors on surge, Protection Cluster	Technical Working Group set in a social context where persons with disabilities were historically segregated	Current, high-profile conflict; largest humanitarian action (11% of total 2022 humanitarian appeal)	In place since 2015, long history. Abundance of tools, broadly inclusive
<b>Venezuela</b> Grupo de Trabajo Sobre Edad y Discapacidad en la Acción Humanitaria	Humanity & Inclusion advisors, CONSORVEN, Protection Cluster	Protection Cluster lead with focal points in different Clusters	Latin America. Humanitarian crisis driven by economic isolation, collapse of government services	Demonstration of how a high-capacity national disability civil society actor can co-lead a meaningful process

Country	Richness of Information	Diversity of Approaches	Audience Interest	Results Achieved
<b>Democratic Republic of the Congo</b> Inclusive Education Network, East Eagle Foundation	East Eagle Foundation founder, UNICEF Education Section, Education Cluster Co- Coordinators	Inclusive education and Education in Emergencies	Localization and the challenges of involving small, local Organizations of Persons with Disabilities in humanitarian action	34 members, 80% local OPDs organized together in a single inclusive education network
<b>Afghanistan</b> Disability Inclusion Working Group	Full-time coordinator, Co-Chairs of Working Group, REACH, Allied cross-cutting groups, Clusters	Example of challenges with linking to Inter-Cluster Coordination Group	Uncertain environment but acute need	Technical support to uptake of Washington Group Questions
<b>Bangladesh</b> Age and Disability Working Group	Current full-time coordinator (national staff), Protection Cluster colleagues, HI office staff as well as OPD members	Refugee response, Protection Sector UNHCR lead	Challenging situation in terms of site, shelter, work/ food and sewage; high risk of sudden onset disaster. Difficult host country context	Improvement of data; increased awareness among sectors, increased influence over Joint Response Plan

### C. Data collection and analysis methods

Key Informant interviews were the primary data collection method following the outline of research questions specified by the project. Initial key informant interviews tended to “snowball” to involve others. Frequently references were made by key informants to documentation or other forms of evidence, such as needs assessment tools or locally prepared guidance. The Humanitarian Info platform was frequently referred to by key informants.

The five case studies in this study have been written in a self-contained manner so that they can be pulled out and shared with local stakeholders. This results in the background sections of each being somewhat repetitive.

# Case Study 1: Afghanistan Disability Inclusion Working Group

## Disability coordination strongly linked to the Inter Cluster Coordination Team

Original humanitarian appeal (\$M 2022)	Revised (\$M, 2022)	% funded as of Nov 18 2022*	PiN (M, 2022)	Persons with Disabilities (2022)	Consecutive years of humanitarian appeals	References to disability in the HRP				
						2019	2020	2021	2022	2023
4,442.2	4,442.2	54.3%	24.4	8.3% (1)	16	48	48	48	156	237

\* as of 18/11/2022 <https://fts.unocha.org/appeals/overview/2022>

(1) With severe disability according to the [Model Disability Survey of Afghanistan 2019](#)

### A. Humanitarian context and disability

The situation in Afghanistan is dire, with a humanitarian crisis that poses a risk of systemic collapse and human catastrophe. The Taliban’s takeover of the country has resulted in rapid economic decline, poverty, a collapsed public health system, and exclusion of women and girls from public life. Afghanistan’s population is expected to grow steeply, and the intertwined environmental, economic, and protection crises will have a far-reaching and potentially catastrophic impact far into the future. In 2023, 28.3 million people will need urgent humanitarian assistance due to drought, climate change, protection threats, and the economic crisis.

The economic crisis in Afghanistan has caused widespread hunger and acute food insecurity, with 6 million people at emergency levels of food insecurity, including persons with disabilities who are particularly vulnerable. Natural hazards like droughts, floods, and earthquakes have also increased humanitarian needs. The Taliban’s curtailment of women and girls’ rights has further restricted their access to essential services, livelihoods, and humanitarian aid, and the directive barring women from working for NGOs will have a devastating impact on millions of vulnerable women and girls across the country.

According to the 2023 Humanitarian Needs Overview, 15% of households in Afghanistan have at least one member with a disability.<sup>7,8</sup> These disabilities often result in higher costs associated with management and a reliance on negative coping strategies due to limited access to assistance. These vulnerabilities also contribute to economic insecurity and higher levels of debt, emphasizing the need for a tailored response that takes into account intersecting vulnerabilities.

In Afghanistan, persons with disabilities face significant challenges due to institutional and cultural barriers, making it harder for them to find employment and achieve self-sufficiency, and exposing them to grave protection risks. As the country faces a dire humanitarian crisis, it is

<sup>7</sup> OCHA, [Afghanistan Humanitarian Needs Overview](#) 2023. p. 11

<sup>8</sup> A 2019 study estimated that “Almost 80% of adults aged 18 and over have some form of physical, functional, sensory, or other impairment (24.6% mild, 40.4% moderate, and 13.9% severe)”, The Asia Foundation, [Model Disability Survey of Afghanistan](#), p.18

critical to prioritize and tailor responses that take into account intersecting vulnerabilities.

In this context, the Humanitarian Country Team called for the establishment of a Disability Inclusion Working Group (DIWG) to play an important role in promoting the inclusion of persons with disabilities in humanitarian assistance efforts through the Inter-Cluster Coordination Team. This case study explores the contribution of a disability coordination mechanism when it is formally integrated into the humanitarian architecture of the response.

## B. Structure

### 1. Dynamics behind the structure and setup of the Disability Inclusion Working Group

The establishment of a joint humanitarian-development disability inclusion working group was first recommended in the multi-year 2018-2021 Humanitarian Response Plan (HRP) updated in 2021.<sup>9</sup> This recommendation was made to address the needs and rights of persons with disabilities in the humanitarian response in Afghanistan. The DIWG aimed to provide guidance, technical support, and capacity building to ensure that the humanitarian response in Afghanistan was inclusive of persons with disabilities.

The updated 2021 HRP described a sector-by-sector detailed description for how issues related to disability would be operationally tackled. With the withdrawal of Western military support by the end of August 2021, and the subsequent take-over of the Government by the Taliban, the initial concept for the DIWG spanning the humanitarian-development continuum, including technical engagement with Government to support policy implementation, had to be rethought. The 2023 HRP describes a scaled-up role for the DIWG, in line with the IASC disability inclusion guidance.

Inclusion of disability-specific indicators in HRP results frameworks is an extremely powerful driver for the DIWG. The 2023 HRP includes seven activity/output indicators across five clusters. In addition to disability disaggregated targets at the operational level, the HRP proposes a budget for the DIWG itself under the heading of Coordination and Common Services.<sup>10</sup>

### 2. Governance tools and hosting arrangements

Disability inclusion was a high-profile issue in the formal humanitarian coordination system already in 2020 when a local OPD (Accessibility Organization for Afghan Disabled, AOAD) was asked to extend its participation in the Humanitarian Coordination Team by the Humanitarian Coordinator.<sup>11</sup> This emphasis on disability inclusion continued through the multi-year HRP process, which made reference to the IASC guidance as one of its drivers. A formal Disability Inclusion Working Group under the Inter-Cluster Coordination Team was established in 2021, but its Terms of Reference had to be revised soon after it was developed prior to the Taliban regime overtaking the capital in May, making the upstream policy influencing aspect of the TOR less relevant, and indeed less feasible.

The current TOR specifies that the DIWG is day-to-day managed by a fulltime Coordinator (fully supported by HI through an ECHO humanitarian grant) and directed by three co-chairs (from the International Labour Organization, UNFPA and Swedish Committee for Afghanistan). OCHA is the formal host agency as the DIWG falls under the ICCT. The HI Afghanistan office provides office space and administrative support to the coordinator.

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<sup>9</sup> OCHA, "Afghanistan Humanitarian Response Plan, 2022", January 2022, p.28. The results framework in the 2018-2021 HRP included considerable detail per sector about disability disaggregated targets, but it was the 2023 HRP which actually included a budget for the Disability Inclusion Working Group (p.163)

<sup>10</sup> OCHA, HRP 2023, p.163.

<sup>11</sup> Stephen Perry and Ricardo pla Cordero, "DFID SBC Afghanistan Case Study", p.4

### 3. Changes over time

Since the TOR was initially prepared in 2021 the Co-Chairpersonship of the DIWG has changed, with a staff person with strong interest in disability inclusion from WFP replacing the Co-Chair from UNFPA. At the time of the case study interviews there was also interest in rebalancing the Co-Chair composition to include an OPD in place of one of the two UN seats, although this change has not yet been made. Including an OPD in a co-chair role would be aligned to the IASC Guideline's recommendation that OPDs be included in inter-cluster coordination meetings.

Some anxiety exists concerning the sustainability of the HI Coordinator's role given the short-term nature of the humanitarian funding that supports it. While initially the level of effort was full-time, it was reduced early in 2023 to 50%.

## C. Set-up

### 1. The identified gaps and needs

The DIWG used a review of the 2022 Humanitarian Needs Overview (HNO)/HRP process to help define which sectors needed to be targeted with technical support support. Following the multi-year HRP which ended just as the Taliban was assuming control, the 2022 HPC produced a needs assessment analysis and plan that was rich in analysis concerning persons with disability. One key gap was the use of disability disaggregated data using the Washington Group methodology. The DIWG was subsequently asked to review needs assessment tools, such as questions in surveys and assessment frameworks. The use and interpretation of the resulting needs assessment data has also been defined as a priority for the DIWG.

Engagement with the key sectors of Protection, Food Security and Agriculture, Health and Nutrition led to quality improvements in the 2023 HNO/HRP with far more rigorous analysis that led to stand-alone disability indicators, as well as other indicators that were disability disaggregated, in the HRP results framework.

Several other gaps have been identified that the DIWG is addressing. For example, it provides responsive support to clusters about how issues relating to disability can be addressed in their programming, with particular guidance on how program mainstreaming can occur. A priority in the coming year is to map the distribution of OPDs in Afghanistan. A third priority issue in line with the IASC guidance is awareness raising of both cluster personnel and OPDs. Cluster personnel have only a limited knowledge about OPDs and their potential role in the humanitarian response while at the same time OPDs perceive humanitarian clusters as simply donors.

### 2. Terms of Reference

The current TOR for the DIWG was revised and updated in June 2022 following the diplomatic withdrawal and evacuation in August 2021. As an inter-agency and inter-cluster technical working group, the TOR specifies a number of specific activities and outputs:

- **Coordination:** through regular meetings, share information and practical guidance with humanitarian actors and raise strategic issues with the Humanitarian Country Team and donors. Strengthen participation of national organisations working on disability.
- **Technical advice, guidance and capacity development in assessments, analyses and monitoring of disability in response:** through technical inputs on needs assessments, guidance on disability inclusion, the use of the Washington Group methodology. Importantly, the DIWG provides specific inputs into the HNO, HRP and the UN Cooperation Framework from the perspective of disability inclusion.



- **Advocacy:** It produces and/or contributes to advocacy briefs on a range of disability topics that are tailored to the local context and local language.
- **Information Management:** It maintains a database of partners providing specialized disability response across the country. Identify and analyses important developments, including needs, response and gaps in disability-inclusive response for sharing and discussion with working group members. Encouraging a more coordinated approach amongst humanitarian and development actors to better serve the needs of affected individuals.
- **Program improvement:** Capacity building in areas like program design, implementation, monitoring, and evaluation.
- **Supporting the development and usage of tools and guidelines:** Tools are intended to reinforce disability inclusion in humanitarian and development responses, in alignment with the IASC Guidelines on Disability Inclusion in Humanitarian Response.

## D. Scope, core-functions, and success factors/challenges

### 1. Coordination and collaboration

The DIWG is hosted by OCHA in its capacity as the secretariat of the Inter-Cluster Coordination Team. Under this umbrella, it maintains strong links and works closely with other coordination structures in Afghanistan response, including:

- Mental Health and Psychosocial Support Working Group
- Accountability to Affected People Working Group
- Gender in Humanitarian Action
- Protection from Sexual Exploitation and Abuse Task Force

These groups are given opportunities on the agenda of the Inter-Cluster Coordination Team's meetings to share information at strategic moments in the humanitarian program cycle. In 2022 the DIWG had this opportunity in September. Figure 1 illustrates the Humanitarian Coordination architecture in Afghanistan.

### 2. Focal points and tools

Only UNICEF among the UN agencies has a designated disability inclusion focal point. The UNICEF focal point attends meetings and briefings on the request of the DIWG, but does not have a formal role in the working group.

### 3. Link with Humanitarian Program Cycle

The DIWG has a designated place in the humanitarian architecture in Afghanistan. Through OCHA, this formal recognition provides a mandate for engagement across the annual humanitarian program cycle with various cluster actors. Its status naturally provides an entry-point for the group to engage in HPC processes, such as reviewing tools and analysis plans developed by REACH for the Whole of Afghanistan MSNA. The DIWG is also expected to provide feedback on the HNO and HRP.

This formal link to the HPC may have contributed to the increase in the number of references to disability in the HRP from 48 in the 2019-2021 multiyear plan, to 237 references in the current

2023 HRP. Much more important than simply referencing disability multiple times however, the current HRP is also very systematic in discussing disability issues in each cluster chapter and framing disability inclusion at the strategic and cluster objective levels.

The development cycle for the HNO and HRP greatly informs the DIWG's workplan. This involves supporting tools development and training for the Whole of Afghanistan multi-sector needs assessment survey, Food Security and Agriculture cluster surveys and Protection cluster assessments. Furthermore, a new tool for protection monitoring developed with the DIWG's support now uses the Washington Group Short-Set Questions.

#### **4. Information sharing**

Monthly meetings of the DIWG take place. In addition, the 2022 work plan described various training opportunities for cluster members, sensitization sessions with the UN Country Team to brief heads of agencies, and input and learning sessions related to needs assessment findings that feed into the HNO and HRP.

#### **5. Success Factors**

An important success factor in Afghanistan that has enabled and promoted the work of the DIWG has been high-level support of the Humanitarian Coordinator's role. Prior to the existence of the DIWG, organizations of persons with disabilities had been invited into the HCT to regularly participate. The formal establishment of the DIWG as a mandated structure with a clear link to the Inter-Cluster Coordination Team facilitated a budget line to be added to the Humanitarian Response Plan, which has given Humanity & Inclusion a framework to seek donor support to support for a Coordinator position.

Within the humanitarian community post-Taliban takeover, the HI Coordinator plays a prominent support role that is recognized by cluster colleagues. Placing individuals with a mandate to help other clusters do their jobs more effectively is appreciated by cluster team members. Key informants report that the DIWG's formal placement within the ICCT elevates the discussion about disability inclusion beyond the level of "box ticking".

The DIWG has kept its TOR and annual workplan living by revising it regularly. A recent example has been the reworking of the TOR to better reflect the Taliban reality, and the reopening of the discussion about DIWG leadership so as to create more space for OPD involvement.

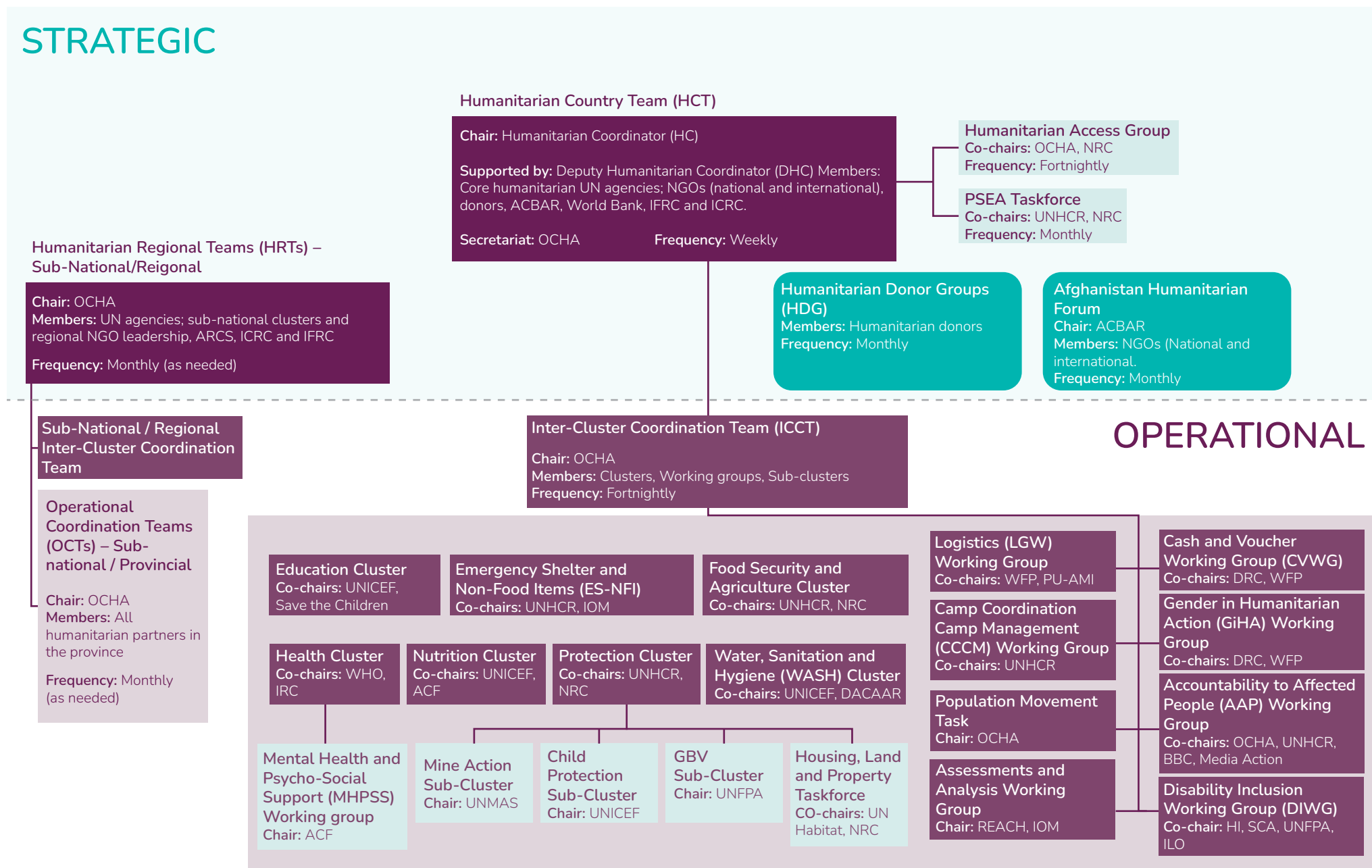
#### **6. Challenges**

Key informants were asked to reflect on the challenges faced by the DIWG. In Afghanistan, as with many other humanitarian contexts, turnover of international personnel is a major continuity issue for the group. Afghanistan is considered a hardship assignment. Personnel are given regular long breaks outside of the country so regular meetings are attended by a rotating array of staff.

Disability inclusion has been identified by the senior humanitarian leadership in Afghanistan as a key issue. Nevertheless, the importance and attention given to the issue by cluster staff varies.

A critical driver of the DIWG is the international Coordinator who is funded 100% by Humanity & Inclusion through a project grant where one of the deliverables is improved coordination. The budget for the DIWG position is included in the HRP's results framework, nevertheless the fund raising required to keep the position staffed is inevitably an unsure process, and this uncertainty takes its toll.

Figure 1 Afghanistan Humanitarian Coordination Architecture (source: Inter-Cluster Coordination Team, Afghanistan)



## E. Leadership

### 1. Leadership setup and practice

Key informants underlined the importance of the coordinator role for the DIWG. Personality matters almost as much as technical contribution and the current Coordinator is very active and supportive within the community. It seems intentional that the HI Coordinator is not one of the Co-Chairs of the group but rather a facilitator of processes. The exact coordination role is not spelled out by the TOR, although it is vital to keep the work plan on track, to arrange regular meetings, and to be available on short-notice to input into processes like the questionnaire design.

The high visibility of the coordinator's role has had other benefits. For example, the Protection Cluster earmarked available pooled funding to disability issues given its confidence that the DIWG would be able to review applications and provide necessary support in a timely manner.

### 2. Engagement of local actors and affected populations

Involving Afghan organizations of persons with disabilities is challenging but important. Local OPDs have been involved in needs assessment processes in the past. However, especially since the change in Government that has resulted in a shrinkage in the space for civil society organizations to operate, the official registration processes for local organizations to be recognized have become opaquer. Mapping of existing OPDs is a 2023 focus for the group.

## F. Added Value of the Mechanism

Key informants were asked what would be lost if the DIWG did not exist. Many reflected about how the voice of persons with disabilities would be missing if a formal channel to amplify this voice was missing. Without the group inclusion would revert to being a "tick-box exercise". As part of the humanitarian architecture, the DIWG receives timely information about coordination issues on an equal footing to other members of the ICCT such as the Accountability to Affected People Working Group, the Gender in Humanitarian Action Working Group and others.

DIWG has been successful at winning and sustaining collaborators at all levels by providing systematic reminders about disability inclusion in programming, and support with tools and capacity building to make this happen through implementing partners.

## Case Study 2: Ukraine Age and Disability Technical Working Group

How a legacy disability coordination mechanism adapts to changing circumstances

Original humanitarian appeal (\$M 2022)	Revised (\$M, 2022)	% funded as of Nov 18 2022*	PiN (M, 2022)	Persons with Disabilities (2022)	Consecutive years of humanitarian appeals	References to disability in the HRP				
						2019	2020	2021	2022	2023
190.4	4,292.5	70.9%	15.7	13.0%	10	24	3	45	63	170

\* as of 18/11/2022 <https://fts.unocha.org/appeals/overview/2022>

### A. Context and background

Issues related to disability inclusion in Ukraine can be understood in terms of three major periods where the focus has changed in terms of disability inclusion, both in terms of the topics as well as the actors involved and their role:

- **1991-February 2014** between Ukraine independence and the Russian annexation of Crimea and the conflict in the eastern Donbas region. The approach to disability inclusion during this post-Soviet period involved the gradual shift towards de-institutionalization and changing attitudes towards persons with disabilities.
- **Between 2015-February 2022** when a humanitarian response was required due to the on-going conflict. Initially the situation had led to a surge in the number of external agencies providing support. The establishment by the Protection Cluster of the Age and Disability Technical Working Group dates to this period. But by late 2021, the humanitarian Protection Cluster was on the verge of deactivating, given the low-level, persistent and unresolved conflict confined geographically.
- **February 2022 to date.** The sudden acute escalation in violence following the Russian invasion of Ukraine resulted in a very large number of internally displaced people, a large-scale refugee crisis, as well as on-going and wide-scale conflict. Ukraine suddenly became embroiled in one of the largest (and best funded) humanitarian crises in the world. A large number of external agencies again surged to provide support.

The Ukraine crisis is rightly referred to as one of the “oldest” humanitarian crises in the world insofar as the average age of persons in need is so high. According to OCHA, over 30 percent of those in need of humanitarian assistance in Ukraine were over the age of 60.<sup>12</sup> They face risks

<sup>12</sup> OCHA, [Humanitarian Needs Overview Ukraine 2019](#), p.7

including limited access to essential services, displacement, and increased exposure to violence. In areas where active fighting was taking place, persons with disabilities are considered the most vulnerable according to a Multi-Sector Needs Assessment undertaken in 2015, followed by older persons. Others were displaced by the conflict requiring support for resettlement and integration into new communities.

Early during this second period there was reportedly also a surge in external humanitarian support flowing into Ukraine.

In this context for seven years the Age and Disability Technical Working Group (ADTWG) has provided a platform for organizations both local and national, working with older populations and persons with disabilities, to come together and share experiences.

## B. Structure

### 1. Dynamics behind structure and setup

The ADTWG was established as a support organization in 2017 following Russian occupation of Donbas and Crimea, and was composed largely of Ukrainian local organizations and institutions. On this foundation a rapid scale-up humanitarian response took place, where contemporary humanitarian protection principles and the Convention on the Rights of Persons with Disabilities had to be reconciled with a century of tradition, where social workers trained on medical and institutionalisation based models of disability.

The ADTWG was led by HelpAge, an international NGO that focuses on advocating for the rights and well-being of older persons. A broad intersection exists between the issues of ageing and disability, and combining the two issues was seen to make obvious strategic sense, particularly in the context of the Russian occupation where a large population of older people did not evacuate, and remained behind the “contact line” separating the Government-controlled territory from occupied areas.

With its significant focus on issues affecting older people, and particularly in these occupied areas, the ADTWG placed less emphasis on the National Assembly of Persons with Disabilities (NAPD), a network of 120 public and Disabled Persons Organizations, although protection and safety of people with disabilities in emergency situations was a strategic focus of the group.<sup>13</sup> The NAPD was established to provide a link to national authorities, inputs into national legislation and policy, counselling on social issues, CRPD monitoring, capacity building, the promotion of accessibility through the principle of universal design, and the protection and safety of people with disabilities in emergency situations.

Recognizing the unusual demographics of the Ukraine crisis the Protection Cluster pushed for the creation of an Age and Disability Technical Working Group in 2015 to “address the particular needs and risks that have arisen in Ukraine for older people and people with disabilities”.<sup>14</sup> According to the original 2017 Terms of Reference for the Technical Working Group, there was no deputy Coordinator position, and HelpAge International has been fully responsible for the coordination role from the start.

The Age and Disability Technical Working Group was established to advocate for the rights and needs of older persons and persons with disabilities. As restrictions were placed even on humanitarian actors working in non-government-controlled areas, considerable attention was

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<sup>13</sup> National Assembly of Persons with Disabilities, “Strategy 2018-2022”.  
<https://naiu.org.ua/strategiya-diyalnosti-vgo-naiu-na-2017-2018-roky/>

<sup>14</sup> ADTWG, “Draft Terms of Reference”, 2015.

placed on capacity building and technical support to local organizations. By 2021 however the pattern of conflict had reduced to a stalemate and discussions were occurring in the Protection Cluster about its deactivation.

In February 2022 that discussion abruptly ended with the Russian invasion. Over a very short period 7.9 million refugees fled Ukraine, and another 5.9 million were internally displaced by December 2022. There has been a resurgence of interest in the ADTWG during this third period in Ukraine's recent history. Again, there has been a rapid influx of foreign NGOs who have come in to support local organizations. An International Organization for Migration general population survey of internally displaced persons (IDPs) found that nearly one-quarter of respondents had a household member with a disability, 39% had an older person, and 30% had a chronically ill member.<sup>15</sup> The same survey reported that social benefits are often insufficient for older heads of households supporting people with disabilities.

## 2. Governance tools and hosting arrangements

Terms of Reference were developed when the group began in 2015 but have never been adapted despite the significant changes in context and need that have occurred. The TOR has now been taken down from [Relief Web](#) and as of June 2023 it has not been replaced. The TOR only superficially describes governance procedures, for example how decisions would be taken. The group is institutionally hosted by the Protection Cluster and fully supported by HelpAge.

## 3. Changes over time

During its initial 2015-2022 period the group was more an information resource platform than a technical working group. Whereas the primary purposes of a TWG is to provide technical expertise, guidance, and support to ensure effective coordination, collaboration, and decision-making, the specific objectives of the ADTWG according to the original TOR were more operational:

- Raise awareness
- Reinforce or build capacities of humanitarian stakeholders
- Undertake service mapping, referral processes and alignment of key protection messages
- Advocacy
- Promote equal and dignified access to humanitarian aid

Main contributions during this initial period included communication tip sheets for different clusters, and establishing a bridge between the Ukrainian Ministry of Social Policy and OPDs. HelpAge tried to merge the resources available for a disability inclusive humanitarian response with the many pre-existing development issues, such as deinstitutionalization, that were prominent in eastern Europe. During the COVID response, the ADTWG disseminated information to raise awareness about the importance of vaccinations.

The 2022 full-scale invasion was a game-changer, involving an extremely rapid escalation in the level of humanitarian support. In 2022 the Humanitarian Response Plan was revised three times, with the appeal increasing from \$190 million to \$4.5 billion over the course of a few months.

Several disability inclusion technical advisors were surged to Ukraine (WHO, UNHCR and

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<sup>15</sup> UN OCHA, "Ukraine Humanitarian Needs Overview 2023", p. 35. Quoting IOM, "Ukraine Internal Displacement Report – General Population Survey Round 9", September 2022

Humanity & Inclusion) to support the ADTWG to consolidate the technical resources it had available to support partners. Key informants described the ADTWG as being less capable on the technical side, although effective in terms of coordination and outreach to Ukraine OPDs and other civil society partners. The ADTWG meets regularly but acts basically as a forum to address very local issues on a case-management scale, including advice on individual referral pathways to an appropriate service provider. In the 2015-22 period this was restricted to the Donbas region but due to the very high number of IDPs the issue is now country-wide and will necessarily involve many new OPDs engaging in humanitarian response for the first time and a new effort will be required to enforce minimum standards.

## C. Set-up

### 1. The identified gaps and needs

The original intent of the ADTWG was to strengthen existing institutions, structures and OPDs in Ukraine. These had no experience or tradition with humanitarian response. Considerable progress has been made to build capacity in this area and raise awareness about how the international system works in terms of the different mandates of United Nations actors. At the same time international agencies and INGOs entering Ukraine following the 2015 annexation needed introductions to civil society actors, and the ADTWG was very effective in making this bridge. However, the ADTWG's work was largely unlinked to the HPC, at least in terms of disability, where issues related to older persons are mentioned twice as frequently as issues related to disability.

A major need moving forward is now recognized as working with the Ukraine Humanitarian Fund, the country-based pooled funding mechanism, to build the capacity of partners to take part in order to expand implementation capacity. There are growing data gaps (which were significant to start with). Ukraine Government disability statistics are not aligned with the Convention on the Rights of Persons with Disabilities (CRPD) as they are presently aligned to the medical model of disability to obtain "official disability status" and trigger social benefits. Adopting a broader social inclusion perspective (as required by the CRPD) would embrace diversity and put a clearer focus on accessibility and equality issues.

### 2. Terms of Reference

While the group has evolved, more attention to adapting the TORs to the current humanitarian context is required to ensure that the group can respond to new challenges. Activities specified in the 2015 TOR were:

- Coordination
- Identification of service gaps and promotion of Protection Cluster referral pathways
- Dissemination of assessments and data
- Capacity building and technical support
- Advocacy and communication

The two points of reference in the TOR are the Humanitarian Inclusion Standards for older people and people with disabilities<sup>16</sup> and the IASC Disability Inclusion Guidance.

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<sup>16</sup> Age and Disability Consortium, "Humanitarian inclusion standards for older people and people with disabilities", 2018.



## D. Scope, core-functions, and success factors/challenges

### 1. Coordination and collaboration

Governance roles in the 2015 TOR mention the HelpAge commitment to provide technical and dedicated staffing support in terms of coordination, and the institutional role of the National Protection Cluster under which the ADTWG would operate.

Regular monthly meetings of the ADTWG occur and involve a broad cross-section of the membership as an open forum. Meetings are open to all UN agencies, national and international NGOs or entities, as well as older peoples' organizations or organizations of persons with disabilities either who have an established presence in the area of intervention within Ukraine, or desire to be. The ADTWG is very open and according to a key informant the at the time of the case study the mailing list included about 300 individuals.

### 2. Focal points and tools

According to one key informant, disability inclusion focal points may exist within agencies but do not play prominent roles. Key informants described a debate about "tokenism" and the expectation for the focal points, where they exist. The concern is that focal points play mainly a representative role in attending meetings. There is also a recognition as with Afghanistan that high turnover affects the continuity of the discussion, and as a result meetings continue to focus on presentations of the latest publication or initiative that an ADTWG wants to share.

### 3. Link with Humanitarian Program Cycle

There is no systematic link between the ADTWG with the HPC, and this was considered a limitation by a key informant.

### 4. Information sharing

Information sharing was a primary purpose of the group in the 2015-2021 period and remains an important emphasis today. A regular monthly letter is produced that updates members on developments, opportunities and links to new tools. The monthly Age and Disability letter typically provides links to:

- Reports and assessments relevant to age and disability
- New Ukraine specific guidance produced by different members
- Training opportunities
- Events
- Advocacy materials

The newsletter is disseminated in both English and Ukrainian.

### 5. Successes and challenges

The ADTWG has raised the profile on the unusual demographic (older people who were the last to consider evacuating following the occupation) of the Ukraine crisis since its inception in 2015. OCHA's assessments have clearly had an emphasis on the particular vulnerability of older persons, and there is a significant overlap between the issues they confront and disability. The ADTWG has been challenged to incorporate issues related to younger persons and children with disabilities, for example inclusive education in emergencies.

The ADTWG has been engaged in advocacy campaigns, such as “Barrier-free Ukraine”<sup>17</sup> that promotes accessibility. It has been engaged in important issues affecting older persons and persons with disabilities, such as pensions, legislation and regulation reform. A challenge for the group is to reconsider the approach to the humanitarian-development nexus, how far policy issues like deinstitutionalization should be prioritized, and how to address needs beyond immediately affected areas in the east and south, to involve places which have absorbed many IDPs such as the west and center of the country where it has not worked extensively in the 2015-22 period.

A significant success has been the national character of the network, involving a large number of Ukrainian OPDs in the network. A challenge has been adapting to the scale and complexity of the post-invasion crisis, to engage and influence the humanitarian system strategically on issues related to disability inclusion.

## E. Leadership

### 1. Leadership setup and practice

HelpAge International has led the group since its inception in 2015, and there is no co-lead. According to key informants, Government representatives have attended the regular bi-monthly meetings but do not have a formal institutional role in the ADTWG.

### 2. Engagement of local actors and affected populations

It is difficult to assess the involvement of disability-focused organizations but the engagement of local actors is a significant contribution of the ADTWG.

## F. Added Value of the Mechanism

The ADTWG’s clear focus on support to civil society in Ukraine, the actors who will stay after the crisis abates, is an important value addition. The group is recognized as a valued platform for information sharing, resources and opportunities. Since 2015 the ADTWG has been an entry-point for local OPDs to contribute to the humanitarian response through introductions to other partners with a similar interest.

If there is a lesson learned related to the experience of the ADTWG it would be the necessity to evolve as the circumstances change. In the case of the ADTWG, as the scale and scope of the humanitarian response escalated, particularly affecting persons with disabilities given the nation-wide impacts caused by the invasion, a reassessment of the role and contribution of the Technical Working Group in light of the changed circumstances would have been appropriate.

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<sup>17</sup> <https://www.president.gov.ua/en/news/pid-chas-vijni-vprovadzhennya-bezbaryernosti-nabulo-she-bils-80101>

## Case Study 3: Bangladesh, Age and Disability Working Group (ADWG)

An NGO driven mechanism coming to shape delivering technical support, influencing response planning & enhancing information on Rohingyas with disabilities

Original humanitarian appeal (\$M 2022)	% funded as of 08 2023*	PiN (M, 2022)	Persons with Disabilities (2022)	Consecutive years of humanitarian appeals	References to disability in the JRP <sub>s</sub>				
					2019	2020	2021	2022	2023
875,9	29,7%	1,52%	12% <sup>18</sup>	10	27	35	15	22	19

\* as of 4/8/2023 <https://fts.unocha.org/appeals/overview/2023>

### A. Context and background

When the persecution and killings of the Rohingya people in Myanmar intensified in 2017, more than 742,000 persons, mostly women and children, including older persons, fled across the Teknaf river into Bangladesh. They joined the more than 200,000 others who had earlier sought asylum<sup>19</sup> in temporary shelters around Ukhiya and Teknaf in Bangladesh's Cox's Bazar district. Existing camps<sup>20</sup> were rapidly expanded<sup>21</sup> and new temporary settlements sprawled in close proximity with host communities. From 2017 onwards, humanitarian agencies upscaled their response and new agencies came in. Insufficient attention was placed on accountability to affected population amidst the scramble to provide basic needs and services quickly.<sup>22</sup> The settlements are all located near the coast and are highly prone to flash flooding as a result of monsoon storms and tropical cyclones.

Rohingyas with disabilities have faced socio-economic and political marginalization in Myanmar since the 1970s. In Bangladesh, their refugee status amplifies manyfold the discriminations they face and risks further disempowering them as rights holders.<sup>23</sup> Amongst the Rohingya people, persons with disabilities face additional stigma and discrimination due to their perceived differences.<sup>24</sup> This multilayered experience of stigma and discrimination hampers their access to basic services, and exposes them to heightened risks of abuse, wellbeing and negative health outcomes.<sup>25</sup>

<sup>18</sup> The disability prevalence rate was not utilized in the 2023 JRP (where there is no reference to disability prevalence) and this estimate was published on a subsequent fact sheet.

<sup>19</sup> From previous displacements dating back as far as 1978, JRP 2021

<sup>20</sup> First settlements were setup since 1991-1992 when Rohingyas fled from Myanmar, mostly Rakhine state, where increased military violence had targeting them. Since then other events (2012 Rakhine State Riots and the 2016 Military Crackdown) triggered further exodus leaving about 200,000 persons living in different sites in Cox's Bazar district.

<sup>21</sup> Kutapalong settlement, near Ukiya, is currently the largest settlement of refugees in the world.

<sup>22</sup> Lough, O., Barbelet, V., Njeri, S., 2022

<sup>23</sup> *Ibid.*

<sup>24</sup> Funke, C. 2021, REACH 2021

<sup>25</sup> *Ibid.*

Following the 2017 influx the main data collection efforts that have been undertaken did not include quality disability prevalence data, despite advocacy urging investments in this area and despite capacity development efforts. The initial registration data collected by UNHCR that continues to be used for Joint Response Plans (JRPs), uses outdated methods resulting in a vast underreporting of persons with disabilities, estimating the number at only 1.52% of the population.<sup>26</sup> Only in 2021 with the help of REACH was a representative household survey undertaken with the support of the Age and Disability Working Group which produced an estimate of 12% of the refugee population having some sort of disability using the Washington Group short set questions.

Rohingyas with disabilities have recently started to raise their voices through informal groups called Disability Support Communities (DSCs) or Disability Inclusion Promotion Groups (DIPGs) in the camps and as individuals, sometimes supported in their setup and communication skills by the Center for Disability in Development (CDD), HI or the International Organization for Migration (IOM).

## B. Structure

### 1. Dynamics behind structure and setup

Interviewees from CDD, Christoffel-Blindenmission (originally, now simply CBM Global) and HI reported that coordination of work began in 2018/19 to begin the process of filling gaps in inclusive data, functional rehabilitation and inclusion efforts, and to answer requests for disability- and age inclusion trainings and technical support. Four organizations – CDD, CBM Global, HI and HelpAge International became the core group of the Age and Disability Working Group (ADWG).

For the first two years of the group's existence, these four organizations rotated the chair of the ADWG every three months. Already by 2019, the core group realized that this part-time arrangement was insufficient to respond to the workload, so the four agreed to fundraise to provide resources for a coordinator role. Despite insufficient resources, they appointed a full-time coordinator in late 2019, defining the coordinator's role around tasks related to technical support, coordination and reporting. Through 2022 the coordinator role had been fully financed.

Initially the ADWG sought members with disability and age inclusion expertise who could actively carry out the five main activities of the ADWG:

- Coordination
- Identification of service gaps and establishment of referral pathways
- Assessment, data collection and monitoring
- Capacity development and technical support
- Advocacy and communication

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<sup>26</sup> Underreported against the global estimate of 15% (recently updated to 16% by the WHO) that is recommended to be used for humanitarian planning when local quality data does not exist.

In 2020, the ADWG opened its membership up to any humanitarian actor who demonstrated a commitment to disability and age inclusion, including the various UN agencies involved in the response, government, civil society, organizations of persons with disabilities and sector working group representatives from Protection, Gender-based Violence etc. Initially there was an application process which confirmed membership, but after 2020 this was abandoned.

In mid-2023<sup>27</sup> the ADWG was dissolved and UNHCR appointed a full-time Age & Disability Inclusion Associate to initiate, convene and facilitate the work of a smaller closed working group consisting of technical expert members only.

## 2. Governance tools and hosting arrangements

Although the initial collaboration began in 2017- 2018, the group's first TOR was developed in 2019 by the four core group members and others in the ADWG.<sup>28</sup>

Since 2022 CDD, HelpAge, CBM Global and HI have been the core leadership group. Any of the four can host the ADWG coordinator, and this position is co-financed by the core group as a whole.

The ADWG's governance, functioning and roles are described in an overarching TOR. Any group member can take on core leadership responsibilities if they are fulfilling three obligations:

1. Fundraising
2. Providing technical experts to the three sub-Working Groups (on Advocacy, Technical Support and Capacity Development)
3. Assigning one staff to play an active role in the core leadership group<sup>29</sup>

Three sub-Working Groups were established in 2019 on the themes of Advocacy, Technical support and Capacity Development, with their functions annexed to the ADWG's TOR. The Coordinator's Job description has been defined by the core leadership. All members are responsible for the annual workplan and are encouraged to join sub-Working Groups in areas where they felt they could add value. Monthly ADWG meetings take place to share information and monitor the work plan.

The ADWG has worked closely with the Protection Sector Working Group (PSWG) since 2020. Beginning in 2022 it had been affiliated with the PSWG although it has no official relationship with either the PSWG or the Inter-Sector Coordination Group (ISCG) until quarter three of 2023. In the third quarter of 2023, the ADWG stopped existing and the ISCG has created a position that will supersede the work of the previous ADWG Coordinator.

## 3. Changes over time

A Disability and Age Task Force came into being with one overall objective: *Promote an inclusive humanitarian response toward persons with disabilities and older persons within the refugee camps and host communities in Cox's Bazar, Bangladesh.* It remained the same over the years until it was dissolved in 2023. The core members expressed their shift in commitment by

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<sup>27</sup> This abrupt change came about after the field work for the case study had occurred.

<sup>28</sup> TORs are reviewed annually.

<sup>29</sup> The scope of work of the leadership group consists of management and capacity development of the ADWG co-ordinator, engage in selected advocacy and representation towards humanitarian leadership, organize an annual advocacy event and attend quarterly monitoring meetings of the ADWG action plan.

evolving from a Task Force to a more permanent Working Group in 2019. Over the years the five specific objectives captured what the group wanted to achieve:

1. Raise awareness regarding the contextual factors that can lead to the exclusion of people with disabilities and older persons.
2. Reinforce or build capacities of humanitarian stakeholders, including relevant Working Groups members, to better understand and respond to the needs of persons with disabilities and older persons through the delivery of inclusive humanitarian assistance.
3. Ensure that persons with disabilities and older people have access to information regarding the humanitarian services available.
4. Support evidence-based advocacy by identifying age and disability concerns and needs, including through joint coordination and assessment with the Protection Working Group (PWG) and any other relevant sector.
5. Promote equal and dignified access of people with disabilities and older people to participatory processes leading to the design and delivery of inclusive humanitarian aid.

During an annual reflection exercise in 2020, two additional objectives were added:

6. Increase the access of persons with disabilities and older people on information and facilities.
7. Strategic collaboration with Protection Sector establishing an agreed technical backstopping plan and tools on age and disability mainstreaming to inform inclusive humanitarian response.

Another shift that was under discussion in early 2023 was the idea of formally affiliating with the Inter-Sector Coordination Group to more closely link the work of the ADWG to the ISCG where there is an ambition to coordinate more effectively with cross-cutting themes. From the ISCG's perspective, the idea is to coordinate action and achieve integration of inclusion as a cross-cutting theme across all sector, not just the Protection Sector.

Another discussion is about whether the focus of the ADWG should remain on capacity development and technical support to current members of the ADWG and sector working groups. As well, the membership structure is under discussion whether it should continue to be limited to organizations with a capacity to provide technical expertise. Questions about the role of the ISCG and its relationship to the existing core-leadership group so as to build on the existing structure are also debated. While the coordinator and current core group members see the advantages of having the ISCG take on more leadership for disability- and age-inclusion, and while they see this may lead to greater attention to these issues in response planning, strategies and related assessments, others in the ADWG were more concerned about the impact of such type of transformational change at operational level.

## C. Set-up

### 1. The identified gaps and needs

Quality disability data continues to be a serious gap that the ADWG continues to address in order to improve inclusive response planning, capacities on inclusive programming, awareness on rights based approach to disability and barriers met by persons with disabilities and older persons. The gaps are reported by members, and funding for main activities is provided by general and core group members.

As gaps are identified, needs are further discussed and addressed by the three sub-Working Groups. For example, upon receipt of a request for technical advice to support the Multi-Sector Needs Assessment, the lead of the sub-Working Group will identify members who are available and knowledgeable in this area in order to provide the support required. For training and capacity development opportunities, ADWG member organizations assess gaps and accordingly identify training and/or capacity development opportunities, and then share information with the whole membership. With advocacy, sub-Working Group members agree on its topics and develop messaging. An example of a key message is that the low disability prevalence rate that continues to be used despite the quality assessment done by REACH in 2021 is a problem.

### 2. Terms of Reference

The Terms of Reference of the ADWG were annually reviewed. While the objectives and main activities had remained the same over time, a major change took place in 2021. It saw the establishment of a core leadership group, the three sub-working groups (Advocacy, Technical Support and Capacity Development) and differentiated functions and roles for coordinator, core leadership group, and members of the sub-working groups, and general members. With the dissolution of the ADWG and its reprofiling a further change will occur.<sup>30</sup>

## D. Scope, core-functions, and success factors/challenges

### 1. Coordination and collaboration

Coordination had taken place via monthly meetings as well as within the sub-working groups. The ADWG Coordinator also engaged directly with all the focus sectors and sub-sector working groups' focal points and provided regular updates during the protection sector meetings. Many requests from members, ISCG and/or sectorial working group for technical support and capacity development were discussed in the ADWG's Technical Support and Capacity Development sub-Working Group. Since 2020, the ADWG had collaborated with the different sectorial focal persons in the annual Joint Response Plan (JRP) – with shared tasks between core group members on influencing via the advocacy sub-working group. Among ADWG members, there is a strong sense that the ADWG provides a platform for collaboration in capacity development, advocacy for better data and meaningful participation of OPDs. Documentation of good practice across the members is shared via newsletter and meetings.

### 2. Focal points and tools

There is no focal point system within the ISCG that would oblige participation and systematic mainstreaming. Yet, some of the sector WGs, such as the Protection Sector WG as well as the GBV sub-sector WG, have appointed a disability inclusion focal person at sectorial level to engage with the ADWG. Over time, taken up on an annual basis, a number of tools were developed fueled by different members' suggestions and funding based on gaps. This takes place in the current setup via the thematic WG. Tools that were accomplished are for instance,

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<sup>30</sup> Following the integration a new ToR will be established superceding the previous one.

an Accessibility Audit tool, Tip Sheets during the Covid pandemic, guidance on assistive devices. The WG also reviews existing inter-agency tools, such as the tip sheets on Child Protection as well as the review of the multi-sector needs assessment tools.

### **3. Link with Humanitarian Program Cycle, joint response planning**

Typical engagements are during the Joint Response Planning (JRPs). In 2020, for instance the ADWG reviewed a tool for proposals submitted during the JRP around the quality of disability inclusion. Other engagements take place during the JRP narrative write up period, by sector.

2019 and 2021 saw quality disability inclusive JRPs, which seemed to coincide with REACH starting to use the Washington Group Short Set of Questions (WG SS) and later the Washington Group enhanced set of questions in an Age and Disability Inclusion Needs Assessment. The highly disability-inclusive JRP of 2021 was characterized by commitments from all sectors to Sex, Age and Disability (SAD) disaggregated data, while few comparable commitments are found in the latest 2022 and 2023 JRPs. This can be explained with shortened and changed formats used for the JRP narrative. The current coordinator reported that better tractions are achieved in the sectorial chapters of the JRP that have appointed focal points on inclusion, who are members of the ADWG. Engagements take place in the advocacy and technical support WGs, as well as in bilateral meeting between the coordinator and the sector coordinators.

### **4. Information sharing**

The ADWG produces newsletters with inputs from the member organizations. The newsletter is shared via a mailing list. It also puts core-documents, including the ToRs and some of the tools, on the protection sector working group's website. As described above, a focus of the ADWG is directed at engaging in processes to obtain better information around the situation of persons with disabilities and older persons in the refugee crisis. Joint rapid needs assessments on the situation of older persons and persons with disabilities were possible to be undertaken in one of the recurrent fire incidents. The information was shared with the wider response.

### **5. Successes and challenges**

**Successes:** The current members see successes in enhanced capacities and awareness around disability inclusion, more and better data on disability from enhancing the use of the WG SS and disaggregating by sex, age and disability (by REACH and others, such as the GBV sub-Working Group members, and GBV JRP partners), better information sharing and support to needs assessments, enhanced inclusion of disability in the JRPs, increasing membership of OPDs in the ADWG. There is wide agreement that due to the ADWG inclusion came on the agenda of the response. Successes were perceived in the joint tool developments<sup>31</sup> and reviews, training activities on disability-inclusive programming leading to more disability-inclusive proposals, changes in organizational policies and better data.

Other successes are changes in the Gender and Age Score, as well as more donors that demonstrated buy-in on disability and age inclusion. Increasingly sectors and the ISCG are reaching out to them on disability inclusion, rather than vice versa. Importantly, referral pathway for persons with disabilities were established, enhancing coordination around access to specific services at the operational level. Available information on DI focal points at camp level for ensuring the referral pathways work are regularly updated and shared via the Protection Sector Working Group. Success factors are the allocation of funding and resources and a dedicated coordinator, as well as for activities, the four core group members' sustained commitment to drive and engage in advocacy since the beginning, the current structure with the effective thematic

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**31** There were numerous tools developed during the ADWG's existence, such as a Accessibility Guidance Tool.



Working Groups, as well as the good relations with Sectors. All members confirmed that the proactive outreach of a coordinator and the work of the thematic WG lifted the inclusion awareness and contributed to a more inclusive response.

**Challenges:** Some important achievements and tools developed in earlier years became apparent only during the key informant interviews that took place for the case studies. Poor information management is linked to the under-resourcing of the ADWG. As many requests for support and technical assistance from the sub-Working Groups are ad hoc, budgeting the time and human resources for inter-agency coordination work is difficult to plan and fundraise for. To meaningfully engage meaningfully OPDs and representatives from the refugees with disabilities, has required additional resources for reasonable accommodation. Financing activities depends on funding, which is always fluctuating and insufficient. Furthermore, funding of activities is not pooled, but stays with the organizations who receive it. Resources are insufficient to support sector Working Groups, such as WASH, Settlement or Education. Recruitment of a coordinator with disability-inclusion and coordination expertise has been a huge challenge in Bangladesh, as such expertise is rare. The coordinator has often requested support from the Disability Reference Group (DRG) to have an opportunity to meet and learn from other coordinators. As a network of peer coordinators from other humanitarian situations does not exist, the ADWG did not have access to tools developed elsewhere. There is an additional challenge on the limited understanding of disability inclusion amongst both affected communities as well as some humanitarian agencies. There is an urgent need to shift from the charity and medical models of disability to one based on social and rights-based approaches.

## E. Leadership

### 1. Leadership setup and practice

Current leadership of the ADWG has driven the inclusion agenda forward, supported capacity development, better data, coordination and fund raising. Nevertheless traction at the response planning level and sustained change in disability data collection has yet to happen. Achievements made can be quickly lost – depending on the shifts in positions. Yet, the current setup doesn't have the reach to influence each of the sectors and resourcing on inclusion. There are different views on future leadership or co-leadership between ISCG and core leadership group. While members and core leadership group would like to expand its work based on established strengths, the ISCG has not attempted to join the core group. Discussions are ongoing on what could work most effectively. It could mean co- or leadership via the ISCG while transforming this NGO co-led, member driven ADWG into a sub-sector WG or a coordinator function on Inclusion.

### 2. Engagement of local actors and affected populations

Around half of ADWG members, including one of the core group leadership members, are local NGOs. As well OPDs from the host community are members, however none of the informal structures – Disability Support Communities or Disability Inclusion Promotion Groups – representing the affected Rohingya population take part.

## F. Added Value of the Mechanism

There is a shared ownership and leadership around strengthened capacities, better data and inclusive JRP's via numerous training initiatives and tools in selected sectors of the refugee response. Across the interviews and workshop all agree that without the ADWG, data would be less. A main added value is seen in a functioning referral pathway at the protection sector for persons with disabilities, including older persons with disabilities at settlement level allowing for smooth referral.

## Case Study 4: Democratic Republic of the Congo, East Eagle Foundation Network on Inclusive Education

### One shape of disability coordination when viewed from the South

Original humanitarian appeal (\$M 2022)	Revised (\$M, 2022)	% funded as of Nov 18 2022*	PiN (M, 2022)	Persons with Disabilities (2022)	Consecutive years of humanitarian appeals	References to disability in the HRP				
						2019	2020	2021	2022	2023
1,881.7	1,881.7	43.4%	27	15.0%	24	0	74	195	-	31

\* as of 18/11/2022 <https://fts.unocha.org/appeals/overview/2022>

### A. Context and background

The Democratic Republic of the Congo (DRC) faces a severe humanitarian crisis marked by conflict, epidemics, natural disasters, and mass displacement, greatly impacting the education sector. Particularly, children with disabilities are amongst the most affected according to the education cluster strategy, with limited access to education and higher dropout rates.

The humanitarian cluster system is in place. Because of the geographic size of the DRC, at the time of the case study cluster coordinators were placed at the national level in Kinshasa with sub-offices situated locally at the regional level where humanitarian situations were being addressed.

The education crisis is significant among the 6.7 million Internally Displaced Persons (IDPs) in the DRC. Out of these, about 2.75 million are school-age children. The situation is gravely amplified for children with disabilities who constitute 22% of the displaced school-age children.<sup>32</sup> They face immense barriers to education, primarily owing to discriminatory practices and a lack of inclusive and accessible education facilities.

Further complicating the issue are the prolonged school closures due to factors like armed conflicts, COVID-19, and teachers' strikes. These closures place children, particularly those with disabilities, at heightened risk of gender-based violence, recruitment into armed groups, and forced labor. Also, schools often become targets in conflicts or are utilized as emergency shelters, further restricting access to education.

Recognizing these significant challenges, the Education Cluster Strategy for 2022-23 plans to address the urgent educational needs of more than 2 million children and 45,000 teachers. The strategy prioritizes creating secure and protective school environments and enhancing the quality of inclusive education.

<sup>32</sup> Education Cluster, "Education Cluster Strategy, Democratic Republic of Congo 2022-2023"

Importantly, the strategy underscores the specific learning requirements of children with disabilities. This includes provisions for physically accessible learning spaces and the distribution of necessary assistive devices. Moreover, there is a strong focus on training teachers for inclusive education, thereby promoting an environment of understanding, acceptance, and support for children with disabilities.

In this education in emergency context the East Eagle Foundation (EEF) – a local network of organizations of persons with disabilities – has sought ways to get involved. EEF was established in 2009 to promote inclusive education. During the course of this work, it has promoted a network of local Organizations of Persons with Disabilities all working in the inclusive education space using a “pragmatist” approach. A pragmatist approach values “decentralized, multi-sited, and horizontal ways of working”<sup>33</sup> in other words, working with what exists rather than imposing a different structure that conforms to an external concept about how the work needs to be organized. The EEF has promoted collaboration by linking-up small OPDs into a loose, informal network. This pragmatist approach is very much in line with the IASC Guideline’s emphasis about the importance of involving Organizations of Persons with Disabilities.<sup>34</sup>

The East Eagle Foundation began to explore engagement with the Education Cluster in 2013 but faced a number of obstacles to engage with the international humanitarian system. Several other initiatives led by local organizations of persons with disabilities have also emerged in the time since, but finding points of connection to Humanitarian Program Cycle processes has been challenging as the default relationship for the international humanitarian system is to use local OPDs and other local actors as implementers or sub-contractors. This case study explores what the network looks like that the EEF has set up, as well as looking at the Education Cluster in DRC, and the challenges it faces when trying to engage local organizations.

## B. Structure of the East Eagle Foundation’s Network

### 1. Dynamics behind structure and setup

The head of the East Eagle Foundation<sup>35</sup> had experience working with the United States Agency for International Development in Kinshasa, where he helped supervise USAID-supported education projects. This was a valuable orientation to the norms and expectations related to international project implementation, but it also provided a connection to a large number of OPDs working on the area of inclusive education across seven Divisions in the DRC. Contacts made at this point in his career were the beginnings of the network.

When the East Eagle Foundation was established, one of its main aims was the attempt to coordinate efforts in inclusive education, to share resources and to work together where opportunities arose. Gradually the number of OPDs loosely affiliated to the network grew. Members followed a consensus model of decision-making as volunteers. From the outset members accepted that participation would require them having their own on-going projects from other donors to fund core costs, as the EEF could not subsidize their participation in the network.

### 2. Governance tools and hosting arrangements

In each of the locations where EEF members are present, one lead organization volunteers to take on the coordination role, arranging meetings with other OPDs in that area on a monthly basis. These lead OPDs then meet together nationally to coordinate and share experiences.

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<sup>33</sup> Fenke Mulder, “Localizing Humanitarian Knowledge Management”, p.228

<sup>34</sup> IASC, “Partnerships and empowerment of organizations of persons with disabilities” in Guidelines: Inclusion of Persons with Disabilities in Humanitarian Action, p.33

<sup>35</sup> John Ntona, <https://eef-drc.org/>

The EEF is not “hosted” by a particular entity, and the arrangement can change over time as different participating organizations grow or contract. There is no single host. The EEF works in a decentralized, multi-sited, and horizontal way.

### **3. Changes over time**

Over time the membership in the network has grown. EEF's own project work in inclusive education funded by various donors put it in touch with new OPDs, growing the network's “map”. Most members are very small organizations, the largest may be Congo Handicap which has about 10 full-time employees. Currently there are 34 members, 80% of whom are OPDs.

Since the EEF was setup, other disability inclusion coordination mechanisms such as the African Great Lakes Initiative for Inclusive Humanitarian Response,<sup>36</sup> the Consortium Congo Handicap et Action Communautaire pour le Developpement Durable<sup>37</sup> or the Agence Congolaise de Promotion des Droits des Personnes Handicapées<sup>38</sup> have appeared, with overlapping membership to the EEF's network.

## **C. Engaging with the Humanitarian System**

### **1. The identified gaps and needs**

An “expectation discrepancy” may exist between what the small local organizations expect from a UN system and what the agencies within the UN system can provide or deliver, and vice versa. The EEF attempted to link with the Education Cluster in 2013, to help design a way to deliver technical assistance supporting inclusive education as a Disability Working Group within the Education Cluster. This idea never got off the ground for lack of funding. Similarly, the EEF reports that it had contacted UNICEF's inclusive education team to provide awareness raising support, but finding an ongoing channel to engage was challenging.

A clear need is to find ways of overcoming the barriers OPDs face is bureaucracy and the weight of social norms in DRC that are not yet in alignment with the Convention on the Rights of Persons with Disabilities. A key informant proposed that the humanitarian response in education could benefit from the contributions of an OPD network, for example, network members can provide data and contacts concerning local disability communities, contribute to needs assessment and analysis, or provide training and awareness building to other NGOs working on the response.

### **2. Alignment between EEF and the Education Cluster's Terms of Reference**

It is not possible to assess a formal TOR for the EEF network as it was not shared, if it exists. The organization's website profiles different strategies it uses in its Inclusive Education and Humanitarian Assistance Programs. Analyzing the key functions outlined in the National Education Cluster's terms of reference compared to the strategies the EEF describes there is considerable overlap. The EEF is naturally more operational in areas such as service delivery support, but it also identifies a role in strategic planning, needs assessment and advocacy.

## **D. Scope, core-functions, and success factors/challenges**

### **1. Coordination and collaboration**

At the present time the Education Cluster is made up of 318 members, including 276 national NGOs, with 22 of these indicating experience related to children with disabilities. This is a large

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<sup>36</sup> <https://africangreatlakes.net/>

<sup>37</sup> <https://www.facebook.com/Consortium-Ch-Acdd-108117064110799/>

<sup>38</sup> <https://www.facebook.com/acpdph.org/>

number of collaborators. The Education Cluster works with the national NGO AIDES (Actions et Interventions pour le Développement et l'Encadrement Social) as an intermediary or liaison with the national NGO partners.

There is a very low barrier to national NGOs to join the Education Cluster, simply a two-page registration form which NGOs complete to be added to the Education Cluster's mailing list. Regular participation by national NGOs in Cluster processes is monitored. When a national NGO applies for access to local Humanitarian Fund resources, its application requires an endorsement from the relevant Cluster. A national NGO applying for funding in the area of education for example, would need the support of the Education Cluster.

## **2. Points of Engagements**

Regional Education Clusters have been established in the DRC at the Regional, Provincial and local levels where required. These structures are responsible for the planning, implementation and monitoring of education in emergency activities, so are more operational in focus. EEF members with active projects participate in these fora.

Key informants report that a barrier preventing active participation in the Education Cluster is logistics. The DRC is an enormous country. To participate in the National Education Cluster's Strategic Advisory Group, an OPD requires a presence in the national capital.

## **3. Making the Link to the Humanitarian Program Cycle**

The current 2022-23 Humanitarian Response Plan in DRC systematically presents an analysis of the number of persons in need with disabilities, as well as the number of persons with disabilities targeted in each cluster.

Making a link between OPDs and the on-going humanitarian response is something of a "catch 22": OPDs with limited means do not have the capacity to get involved, yet there are constraints to growing their budgets unless they get involved. Their regular participation in coordination mechanisms like the Education Cluster is limited due to their resource constraints but without visibility there gaining the endorsement to access local humanitarian fund resources. The EEF also reported that applications for funding require a demonstration of financial management performance based on previous grants. Practically local organizations also need logistical capacity in order to participate (vehicles to travel to the meeting, communications or internet connectivity to participate on-line) and these are very small organizations with very limited budgets and staff.

## **4. Working Horizontally**

As a network of organizations of persons with disability its members can and do work together, for example on funding opportunities, by pooling their collective experiences and capacities in proposal development processes. Members are encouraged to leverage their affiliation to EEF in funding applications. The "decentralized, multi-sited, and horizontal ways of working" facilitates the sharing of inclusive education materials and other resources among members, avoiding excessive duplication of effort. Working in this way as a network, where 80% of the membership are OPDs, distinguishes the East Eagle Foundation from other mechanisms contributing to the coordination of disability inclusion.

The UNICEF Education Team in DRC envisages a role for an OPD network such as EEF beyond data collection, materials dissemination and capacity building (the more typical activities OPDs are assigned) to participate in and contribute to higher level processes, such as contributing to strategy development related to inclusive education. The National Education Cluster's TOR also does allow for Thematic Groups to be established at either the national or regional level as required. The EEF could potentially engage with other organizations in the Education Cluster as a Thematic Group focusing on inclusive education issues.

The Education Cluster also has the scope to incorporate the contributions of time-bound, task-oriented “Technical Working Groups”, for example to define minimum standards or set out technically appropriate best practices. TWGs have the potential of being very influential, as they impact the work of all organizations under the Education Cluster. The strategy of the EEF to design training materials for teachers and principals of primary and secondary schools is the kind of topic that a TWG could engage in.

### **5. Added Value of the Network**

The EEF has cited evidence that its network members have contributed disability prevalence data that has been used by local government in targeting humanitarian assistance. It has cited examples of awareness raising events and trainings where its members have worked with local government and non-OPD local organizations to build their capacity. It claims that its approach to these events is somewhat unusual as training participants are intentionally not compensated for their attendance, in the same way that EEF members participate voluntarily in the network.

### **6. Future Possibilities**

The East Eagle Foundation’s approach suggests a pathway by whereby small, local OPDs can aggregate their efforts in order to have a louder voice in areas like inclusive education in emergencies. Although the EEF has not yet managed to achieve this, the original concept was to create a network that had the possibility of going to scale.

## Case Study 5: *Venezuela Grupo de Trabajo sobre Edad y Discapacidad en la Acción Humanitaria*

A local OPD building confidence to engage in humanitarian coordination with HI's support

Original humanitarian appeal (\$M 2022)	Revised (\$M, 2022)	% funded as of Nov 18 2022*	PIN (M, 2022)	Persons with Disabilities (2022)	Consecutive years of humanitarian appeals	References to disability in the HRP				
						2019	2020	2021	2022	2023
795.0	795.0	36.1%	5.2	12.0%	5	6	-	11	21	21

\* as of 18/11/2022 <https://fts.unocha.org/appeals/overview/2022>

### A. Context and background

The protracted socio-political situation in Venezuela is creating grave humanitarian implications for its citizens, particularly vulnerable groups like persons with disabilities. Massive hyperinflation and import restrictions have reduced access to basic necessities like food, medicine, and other essential goods. The economic situation has driven an alarming 94.5% of Venezuelans into poverty,<sup>39</sup> with multidimensional poverty indicators showing significant deterioration in education, housing, access to public services, income, and employment.

Persons with disabilities, comprising a considerable proportion of the vulnerable population, are particularly impacted due to a combination of systemic discrimination, inadequate disability-inclusive services, and the unique challenges imposed by the barriers they face. The scarcity of resources, for instance, also means a shortage of specialized support and assistive devices they might need for mobility and communication, consequently restricting their independence and societal participation.

The healthcare situation in Venezuela, marked by a shortage of medical supplies, departure of medical personnel, and resurgence of preventable diseases like measles, also disproportionately affects persons with disabilities. Their health needs can be complex, requiring regular and specialized care, which is largely inaccessible in the current context.

The role of organizations such as the Confederación Sordos de Venezuela (CONSORVEN)<sup>40</sup> is paramount in the current context. CONSORVEN has been advocating for the rights of persons with disabilities, striving to ensure they are included in mainstream society and their specific needs are met.

<sup>39</sup> ACAPS, "Crisis Updates – Venezuela", December 2021 (<https://humvenezuela.com/wp-content/uploads/2021/12/Venezuela-Complex-crisis--ACAPS.pdf>) Citing the 2021 Living Conditions National Assessment.

<sup>40</sup> <https://consorven.org/>

The particular challenge facing CONSORVEN, and other Venezuelan organizations of persons with disabilities, is that they had little background or experience as humanitarian actors prior to the current situation. Although the country is at risk to natural disasters – such as earthquakes or floods – and has had notable periods of political unrest in the past, until recently revenues from its natural resources were used by the Venezuelan State to fund a high level of social services that masked the underlying disaster risk vulnerability. In the current context these social services have disappeared.

The Venezuelan state has been historically suspicious of outside interference, and this has been exacerbated in the current situation by the sanctions regime. Significant constraints have been placed on international organizations, including the United Nations and INGOs like Humanity & Inclusion. This case study looks at how a disability inclusion coordination mechanism can be led by a national organization, with international support backing them up in order to engage with unfamiliar requirements of different humanitarian program cycle processes.

## B. Structure

### 1. Dynamics behind structure and setup

The humanitarian cluster system was activated in 2019 as a response to the severe economic hardship resulting humanitarian needs across the country.

It was originally envisaged to locate disability inclusion as a thematic issue in the humanitarian response under the Inter-Cluster group, but there was neither capacity nor interest on the part of the other Clusters who were comparatively less well staffed. The Age and Disability Working Group in Humanitarian Action (Grupo de Trabajo sobre Edad y Discapacidad en la Acción Humanitaria -- GTEDAH) was established by the Protection Cluster in 2020 which recognized a significant gap and the opportunity to advance protection mainstreaming principles.

A partnership of two pairs of organizations were invited by the Protection Cluster to support the GTEDAH: CONSORVEN in partnership with Humanity & Inclusion, and the national NGO Convite<sup>41</sup> in partnership with HelpAge International. Due to bureaucratic barriers to being legitimized, INGOs need local partnerships to begin working quickly. The INGOs may be in a stronger position to attract funding, but the local partner can provide an implementation pathway, and as importantly, knowledge of the local context. As well, in the case of CONSORVEN, the President is experienced in advocacy, campaigning and good political links, and was recognized as the Vice President of RIADIS (the Latin American Network of Organizations of Persons with Disabilities and their Families). CONSORVEN had an interest to continue their existing partnership with Humanity & Inclusion and expand cooperation in the field of strengthening the mechanism for coordination in humanitarian action.

### 2. Governance tools and hosting arrangements

The GTEDAH is hosted by the Protection Cluster, and a Plan of Action is currently under development. The Protection Cluster acts as gate keeper, channelling and prioritizing the many requests that have already been received to provide capacity development and awareness raising.

### 3. Changes over time

Participation in the GTEDAH has been stable, although active engagement has been limited to the two pairs of organizations: CONSORVEN/Hi and Convite/HelpAge. The group recognizes the cross-cutting nature of the age and disability issues and encourages more members, and a

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41 <https://conviteac.org/>



key focus is on growing the number of organizations who are engaged. The Terms of Reference mentions the participation of Areas of Responsibility under the Protection Cluster in Venezuela (Child Protection, Gender-based Violence and Protection from Sexual Exploitation and Abuse), other Clusters and OCHA. Although some interest has been reportedly shown by the Food Security and Education Clusters, these are not currently members. GTEDAH members also indicate that LGBTQI+ groups in Venezuela have shown interested in joining this inclusion coordination mechanism.

## C. Set-up

### 1. The identified gaps and needs

Venezuela has little official data given the sensitivities of the political situation. Also given the massive population movements as a result of the crisis, there is very little current information that could help inform a needs assessment process.<sup>42</sup> OCHA recognized the gap, especially in terms of disability disaggregated data.

Age and disability issues are very important in this kind of humanitarian emergency, where social support networks have been massively disrupted due to displacement. Despite the importance of age and disability issues, large interventions have been initiated in the Venezuela response with little integration of disability-related issues.

### 2. Terms of Reference

The Terms of Reference was prepared by the Protection Cluster and revised in 2021.

Objectives and Activities as spelled-out in TOR:

- **Identifying Gaps in Inclusion:** Identifying existing gaps in the inclusion of older adults and people with disabilities in the humanitarian response through Identification and Needs Analysis.
- **Raising Awareness:** Conducting training, sensitization and advisory activities for humanitarian actors and interested parties to highlight the importance of inclusive humanitarian action.
- **Capacity Building:** Strengthening the capacities of humanitarian actors from different sectors to enable them to carry out inclusive humanitarian action.
- **Promoting Accessibility:** Promoting the use of accessible formats for information related to humanitarian assistance and systematizing available services and resources to support the response.
- **Overcoming Barriers:** Generating proposals to overcome barriers faced by people with disabilities and older persons in accessing humanitarian assistance and establishing accessible care routes based on detected barriers.
- **Resource Development:** Creating reference documents, protocols, and

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<sup>42</sup> There has never been a Humanitarian Needs Overview published for the Venezuela situation. Instead, Venezuela produces a hybrid Humanitarian Response Plan that includes some assessment information. Given the acute sensitivity, the use of language has to be very diplomatic for example the country has humanitarian “priorities” not “needs”. In this context it is unsurprising that the situation of persons with disabilities is given only a low profile to avoid implied criticism.

guides to provide materials on issues related to inclusion and best practices.

- **Supporting HNO and HRP process:** specifically, providing assistance to the 2021 Humanitarian Response Plan.
- **Planning:** Developing an annual work plan detailing the sector's responsibility and committed resources to achieve the expected objectives.

## D. Scope, core-functions, and success factors/challenges

### 1. Coordination and collaboration

The Protection Cluster co-leads the Age and Disability Working Group together with CONSORVEN and Convite.

Given the cross-cutting nature of the age and disability approach, the TOR envisaged an intersectoral character for the Working Group involving the participation of different clusters and areas of responsibility. In actual practice, with the high workload and the limited resources available to the response, other Clusters and Areas of Responsibility are not actively involved in the Working Group.

### 2. Focal point approach

There are no disability inclusion focal points in other Clusters or implementing agencies.

### 3. Link with Humanitarian Program Cycle

The TOR specifically associates support by the GTEDAH to the HNO and HRP development process. It was reported by key informants that members of the working group have been involved in HPC processes in a number of different ways, including:

- the collection, analysis and use of data disaggregated by gender, age and disability
- training, sensitization and advisory activities
- preparation of reference documents, protocols and guidelines to reflect good practice
- the establishment of accessible care pathways based on its analysis of barriers

### 4. Information sharing

Annually in November there is an opportunity to engage via the Protection Cluster in a meeting where all sectors and working groups are invited. GTEDAH members attend this forum. GTEDAH is not referenced on the OCHA micro-site for the Venezuelan response.<sup>43</sup> Meeting minutes are not publicly available.

## E. Leadership

### 1. Leadership setup and practice

The GTEDAH is co-led by the Protection Cluster, CONSORVEN and Convite. As CONSORVEN

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<sup>43</sup> <https://response.reliefweb.int/venezuela>

is developing its capacity in the humanitarian area, where it had no experience until 2019, HI closely supports CONSORVEN and helps it raise standards. As a result, the technical capacity of CONSORVEN is increasing.

## **2. Engagement of local actors and affected populations**

CONSORVEN is a prominent local actor, as is Convite. Engagement in the Humanitarian Response Plan is open to the participation of all Protection Cluster's partner organizations, who may participate in consortia with CONSORVEN and Convite, or independently as is the case of Hábiles and FUNDAFID. HI also works with other OPDs which specialize in other impairments besides hearing. Through trainings provided to partners and agencies, GTEDAH has had an influence on the work of other agencies. For example, CONSORVEN and the Protection Cluster Interlocutor have provided an orientation to the International Organization for Migration on how to prioritize persons with disabilities in its temporary refugee programs.

## **F. Added Value of the Mechanism**

The GTEDAH seems to fulfill a growing appetite by Clusters and agencies to benefit from training and awareness raising around disability inclusion. This value is added through the strong complementarity between the Protection Cluster, a strong national actor and an international NGO. Each balances the others' strengths and weaknesses. Through this collaboration key informants pointed to specific examples where program designs were adapted towards being more disability inclusive following awareness raising and technical support in this area.

The first Venezuela Humanitarian Response Plan included programmes targeting persons with disabilities. These were prioritized through a CERF under-funded allocation in August 2019. In that funding cycle, persons with disabilities were identified as one of the four underfunded areas that were prioritized through "strategic steers".<sup>44,45</sup> In 2021 through this window 12.5% of the CERF budget was allocated to assist people with disabilities.<sup>46</sup> Interest and appetite among humanitarian actors to learn more about how persons with disabilities could be involved may have been triggered by this funding focus. A mapping conducted as an input into the 2022-23 HRP indicated that 47% of projects consulted people with disabilities or specialized organizations in the project design process, and that an estimated 12% of the target population were people with disabilities.<sup>47</sup>

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<sup>44</sup> MOPAN Assessment Report, "United Nations Office for the Coordination of Humanitarian Affairs 2020 Assessment Cycle", p.39

<sup>45</sup> OCHA, Global Humanitarian Overview 2021, "Pooled Funds and Humanitarian Emergencies"

<sup>46</sup> OCHA, Humanitarian Response Plan 2022-23 Venezuela, p.9

<sup>47</sup> *Ibid.*, p.14

# Comparative Analysis

## A. Similarities and differences in coordination mechanisms

Across the five cases of Afghanistan, Ukraine, DRC, Bangladesh and Venezuela, a common pattern leading to the establishment of Disability Inclusion Coordination Mechanisms appears to be the recognition of disability as a key issue in the context of a humanitarian crisis and response. Humanitarian response actors (clusters, sector working groups, operational actors such as REACH) look to specialized organizations such as HI or HelpAge to provide support around disability inclusion which drives the creation of these groups. Despite unique situational triggers, these patterns suggest that the recognition of the need to include disability inclusion considerations in humanitarian responses, alongside existing operational setup and capacities of disability-inclusion focused organizations, are critical in the initiation of such coordinated mechanisms.

These case studies were selected to illustrate differences across five different hosting scenarios: the disability inclusion coordination mechanism in Ukraine and Venezuela was with the Protection Cluster, in Bangladesh in affiliation with the Protection Sector Working Group, which is a common arrangement. In the DRC the inclusive education network that was profiled was independent, “decentralized, multi-sited, and horizontal” although it had attempted to link with the National Education Cluster. In contrast, recognizing the cross-cutting nature of the disability inclusion issue, and the capacity gap amongst humanitarian actors, the mechanism was linked to the Inter-Cluster Coordination Team facilitated by OCHA in Afghanistan.

Terms of Reference were common organizational features that helped shape the work of these different mechanisms. At the same time, it seems TORs quickly lose their relevance. Up to date workplans were seen only in Bangladesh and Afghanistan.

Coordination and leadership arrangements varied quite considerably with different models depending on complexity, history and resources. Where the Coordinator of the inclusion mechanism is fully funded, such as in Afghanistan, Bangladesh and Ukraine, the mechanisms obviously work the best. The coordination mechanisms in Bangladesh and Venezuela and the inclusive education network in DRC are led or co-led by local Organizations of Persons with Disabilities. At the time of the case study the coordination mechanism in Afghanistan was co-chaired by UN members and an INGO, with a coordinator from an INGO.<sup>48</sup> Bangladesh and Ukraine have core leadership setups or lead agencies that are filled by inclusion-focused INGOs.

Across the cases studies, the coordination structures reveal a pattern of dynamism and adaptability in response to evolving circumstances, characterized by changes in leadership, membership, operational focus, and advocacy priorities. In Afghanistan, for instance, the shifting nature of the co-Chairperson architecture seems to reflect a sincere attempt to balance participation given how the group is linked to the Inter-Cluster Coordination Team. Changes in Ukraine have been largely driven by external political factors, where the full-scale invasion in 2022 may have triggered a drastic re-think about the role of the Age and Disability Technical Working Group from primarily an information resource towards something more technical, although this change has not yet happened. Changes in the coordination apparatus in Bangladesh was driven by the need to address gaps, making the group more effective, responsive and agile.

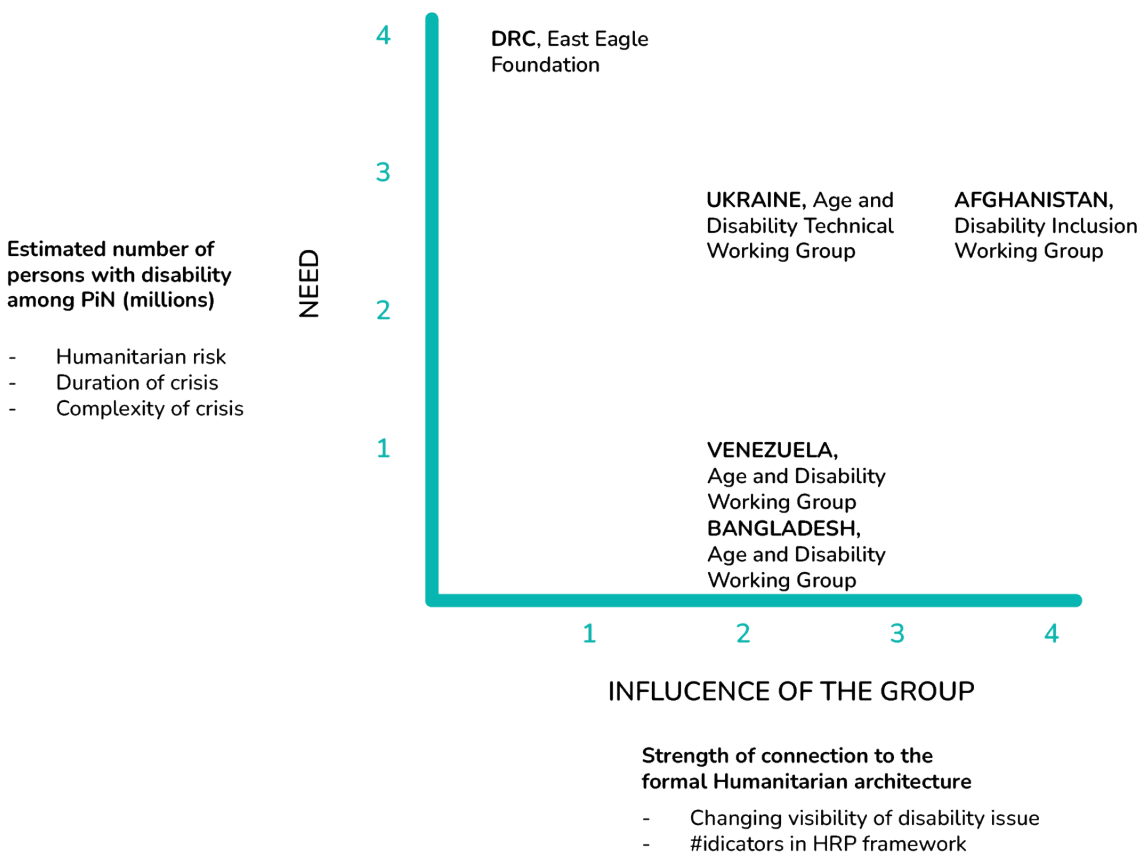
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<sup>48</sup> Since the data collection for the case study was collected, a local OPD has agreed to co-Chair the DIWG in Afghanistan.

## B. Need versus Influence of the Group

The five cases can be compared considering their local context and the level of influence the group has amongst humanitarian actors. The diagram (Figure 2) compares “need” as defined by the number of persons with disabilities in need (using the proportion of persons with disabilities as reported in the HRP in terms of the total number of Persons in Need) versus the influence of the group on the system (low, medium or high considering the link to the humanitarian coordination structure).

**Figure 2 Humanitarian need versus the influence of the group**



This comparison suggests that given the high humanitarian need in the DRC, for example where 22% of out of school children targeted by the Education Cluster are children with disabilities, and where the population of persons with disabilities is nearly four million, it is unfortunate that the disability inclusion coordination mechanism identified there has so little connection to the formal humanitarian architecture. It also suggests that the link to the Inter-Cluster Coordination Team in Afghanistan is an appropriate solution in a humanitarian context where the number of persons in need with disabilities approaches two million. In Bangladesh the influence of the group is credited to its affiliation with the protection cluster and focal points in other sector working groups which has made work on improving data and enhancing inclusiveness in the Joint Response Plan more effective and efficient. Despite recent advances, the current conversation in Bangladesh is about the need for the ADWG to take on a formal status in the Inter-Sector Working Group with stronger links to a UN agency, in order to produce traction on the disability inclusion agenda.

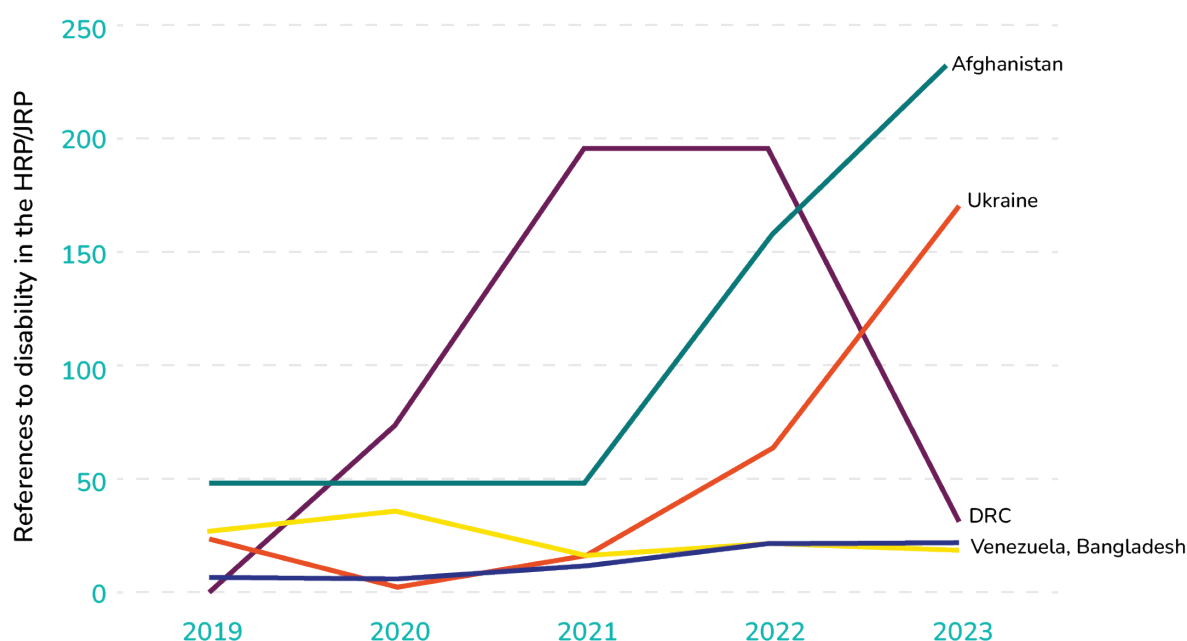
## C. Success factors and barriers

A common thread woven through the five examined cases is the gap in producing and interpreting disability data. The necessity to better integrate disability into programming, offer guidance on mainstreaming, raise awareness about the role of OPDs, and foster meaningful engagement with a broader spectrum of stakeholders also emerges across the case studies.

### Gaps in Collaboration

Critical gaps in collaborations are also apparent. The potential for more direct engagement with local government institutions is hinted at but remains unfulfilled. For instance, in DRC, the Ministry of Education and Ministry of Social Affairs are mentioned as potential partners, though bureaucratic hurdles prevent effective collaboration. In Ukraine, the large National Assembly of Persons with Disabilities is a member of the ADTWG but not in a leadership role. Only in Afghanistan and Ukraine is there a clear trend in terms of reflecting disability issues more prominently in HPC products such as the Humanitarian Response Plans (Figure 3). Once all coordinators and focal points from other sectors began regularly participating in ADWG processes in Bangladesh its input into the Joint Response Plan was taken more seriously. The ADWG's "good problem" to have was the significant demand by different sectoral working groups for its technical support, given its limited resources.

**Figure 3 References to disability in the HRP or Joint Response Plan**



### Diverse Tools and Approaches

These cases reveal a diverse range of tools and approaches used for coordination among humanitarian actors and collaborators. Although a focal point system was recommended in the IASC Disability Inclusion Guidance on Disability Inclusion there does not appear to be much traction for this, and in only one of the cases were focal points engaged (if they were named at all). In Cox's Bazar in Bangladesh some of the sector working groups have appointed inclusion focal persons from lead agencies to attend the ADWG.

The importance of the multi-sector needs assessment survey exercises which feed into the Humanitarian Needs Overview, on which basis the HRP or JRP is prepared, is a central focus of the DIWG in Afghanistan and ADWG in Bangladesh, but not in the other three cases. An optimal entry point for involvement in the HPC and joint response planning would integrate these groups at various stages of the cycle, such as tool review, needs assessment, and strategic planning,

while providing resources and support for local organizations to effectively participate and influence decision-making processes.

### **Organizations of Persons with Disabilities**

Much can be learned from the experience of the East Eagle Foundation in terms of the barriers local organizations encounter when attempting to contribute to humanitarian responses. An “expectation discrepancy” exists between what the small local organizations expect from a UN system and what the agencies within the UN system can provide or deliver, and vice versa. If the humanitarian system is serious about localization and involving OPDs it may be worth exploring what Cluster processes require, and what OPDs expect to receive from the system. DRC’s scenario illustrates the “Catch-22” dilemma for local organizations - they need the resources that participation in the HPC could facilitate, yet they lack the means to participate effectively in HPC processes.

The East Eagle Foundation’s network organizational structure evolved in an autochthonous manner, without following the direction of an external model for how a network should look. In the other cases the coordinating mechanism was defined based on a terms of reference template similar to other humanitarian working groups.

Currently in Bangladesh, Afghanistan and Venezuela OPDs play a prominent leadership role. In some cases OPDs are given support to attend working group meetings.

### **Dissemination of Information**

The manner in which disability-related information is disseminated varies across the cases, exhibiting a mix of traditional and innovative methods. In Afghanistan, a structured approach involving regular briefings, meetings, and co-chairing arrangements fosters consistent information exchange, bolstered by a full-time coordinator. Ukraine’s ADTWG utilizes digital resources, such as online repositories and monthly newsletters, albeit with some concerns about the nature of the content and accessibility gaps. In Cox’s Bazar the protection sector regularly shares tools produced by the ADWG on its website and a monthly newsletter keeps the group’s membership updated on good practices, upcoming events and key developments (although mostly in the English language). While various methods offer different benefits, the overall sharing of information could be enhanced by ensuring updated content, integrating multi-lingual and accessible materials, promoting active participation, and leveraging digital platforms for continuous and broad engagement.

### **Localisation**

In the five cases examined, the engagement of local actors in the disability inclusion coordination process varies significantly. In Afghanistan, the opaque registration process for Civil Society Organizations (CSOs) under Taliban rule has hindered their engagement. In Ukraine, while the impression is that many local OPDs are on the mailing list, the National Assembly of Persons with Disabilities is involved, but local organizations lack leadership engagement. One of the four organizations in the core leadership group of the Bangladesh ADWG in Bangladesh is a local organization, and OPDs from host communities are engaged as working group members. However because meetings are presently only organized in Cox’s Bazar<sup>49</sup> representatives from the informal groups of refugees with disabilities face a barrier to participate. In DRC, local actor engagement is active in the education sector; however, its reach is severely limited due to capacity constraints. In Venezuela and Afghanistan, Humanity & Inclusion has conducted capacity-building trainings with local partners, reflecting a proactive approach to foster engagement. Despite these efforts, common barriers preventing greater engagement include restrictive governance structures, hierarchical relationships, lack of capacity or resources, and

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<sup>49</sup> The closest refugee settlements are more than one hour away from Cox’s Basar, which is where most of the coordination meetings take place.

limited specialist knowledge or expertise in inclusive humanitarian action. The inclusion of local actors in leadership roles, particularly organizations of persons with disabilities is crucial for creating and implementing more responsive, effective, and sustainable humanitarian strategies.

### **Intersectionality**

Lastly three of the cases (Bangladesh, Ukraine and Venezuela) were coordination mechanisms that addressed the intersectionality of age and disability, while the other two (DRC and Afghanistan) focused more directly on disability issues. Both persons with disabilities and older individuals face some common and unique challenges during humanitarian crises. Some barriers are faced by persons with disabilities and older persons equally. Older persons are more likely to have disabilities. However younger persons with disabilities are more likely to encounter stigma. Combining the two issues can therefore confuse and reduce the focus and accountability for addressing their specific needs.

At the time of the case study in Ukraine the ADTWG does not address issues related to children with disabilities arguing that this is UNICEF's mandate.

In Venezuela where age and disability are considered in the same working group, there is now an interest to add LGBTQI+ issues because of the growing demand for awareness raising in this area. It is understandable given the proliferation of cross-cutting issues that accommodations need to be made given resource and attention limitations, but at the same time the skillsets needed to address data collection issues, for example, are very different depending on the identity being considered.

A need exists to simplify the humanitarian coordination architecture. In just the Protection Cluster alone there are a proliferation of sub-clusters, working groups, and task forces as well as different Areas of Responsibility including child protection, gender based violence, housing land and property, and mine action. The Protection Cluster also formally addresses several cross-cutting themes that are integrated across these AoRs including accountability to affected populations, age gender and diversity and community-based protection. Simply adding another mechanism to an already crowded structure may not solve the problem of providing the necessary support to the issue of disability inclusion in the HPC.

Drawing inspiration from the experience of how gender has been increasingly mainstreamed into humanitarian action, it was a long-term process facilitated by a series of reforms backed up with technical and political support. It required more systematic 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 feature of the humanitarian architecture. Such mechanisms might even do more harm than good if they compartmentalized the issue of disability inclusion, leaving the impression that the challenge has been sufficiently addressed. Where these mechanisms could be useful over the short- and medium-term as seen in these case studies is to provide an organizational platform for the coordination of disability inclusion focal points coming together from across agencies. Disability inclusion focal points is something assumed by the Guidelines for the Inclusion of Persons with Disabilities in Humanitarian Action as a norm, but was something that was not observed as a common practice in these case studies. Exploring why the disability inclusion focal point approach has not been adopted, or what alternatives exist to stand-alone mechanisms for the coordination of disability inclusion could be the focus of a future study in this area.



## D. Lessons learned from each context

In the case of **Afghanistan**, the key lessons highlight the importance of integrating disability considerations into the overall humanitarian program cycle, the necessity of a full-time coordinator, and the crucial role of sustainable funding. These elements combined promote the overall effectiveness of disability inclusion coordination. Furthermore, turnover or absence of international personnel due to hardship can pose challenges, thus reinforcing the need for stable, long-term commitment to disability inclusion.

In **Ukraine**, the strong national character of the inclusion coordination mechanism underscores the importance of context-specific approaches. Furthermore, the engagement in significant advocacy issues illustrates the benefits of taking a comprehensive view of disability inclusion, not only focused on immediate assistance but also on broader policy reform. However, the lack of systematic engagement in the Humanitarian Response Plan (HRP) process highlights a missed opportunity for influence and integration.

In **Bangladesh**, having four co-leads including a local disability inclusion NGO has encouraged strong membership engagement by OPDs, civil society groups, INGOs and sectorial inclusion focal points. Active members are encouraged to share their expertise with others in the group. Its fully-financed coordinator is another obvious success as it provides continuity and follow-up. is a third element that helped the ADWG.

The **DRC** experience reveals the benefits of collaborative work and the value of creating an interconnected network for information sharing and pooling resources. Yet, it also emphasizes the need to empower organizations representing persons with disabilities. The case reveals the paradox that without sufficient resources to engage, organizations may struggle to get involved in coordination processes.

Lastly, in **Venezuela**, the process of raising awareness about disability and its contributions to the HRP demonstrated a valuable strategy for changing attitudes within implementing agencies. This points to the potential power of awareness-raising and advocacy within the humanitarian field. The sensitivity of the political environment, however, poses challenges, highlighting the need for careful and considerate approaches to disability inclusion in such contexts.

## E. Significant results and value addition

In humanitarian crisis contexts, effective disability inclusion mechanisms have proven instrumental in steering aid strategies towards more inclusive, equitable, and efficient solutions. By facilitating the active participation of people with disabilities, these mechanisms serve to both amplify marginalized voices and enhance the overall effectiveness of humanitarian interventions.

**Afghanistan:** The Disability Inclusion Working Group (DIWG) in Afghanistan has fundamentally reshaped the approach to disability inclusion, transforming it from a mere tick-box exercise to being a core component of the humanitarian response. OPDs have gained capacity and recognition so that they are in a co-leadership position contributing to the working group to the humanitarian program cycle and its processes.

**Ukraine:** In Ukraine, the disability inclusion mechanism has emerged as a pivotal platform for information sharing, resource allocation, and opportunity identification. Notably, it has provided local Organizations of Persons with Disabilities with access to the broader humanitarian sphere, fostering greater inclusivity. Its advocacy work around pension reform is another key achievement, demonstrating the power of such mechanisms to effect meaningful policy changes.

**Bangladesh:** The mainstreaming of disability inclusion in the refugee response is making progress in important areas including improved data on disability as well as stronger collaboration with lead agencies and sector working groups. ADWG member organizations have appreciated the capacity development and technical support provided by the inclusion-focused agencies that helped them deliver improved services in various sectors on the ground.

**DRC:** The mechanism in the DRC has taken an inclusive, participatory approach to service delivery in the education sector, embodied in the principle of “nothing about us without us”. It is one model of what a “decentralized, multi-sited, and horizontal” disability inclusion coordination may offer a better approach to localization, especially where the OPDs involved are extremely small, often volunteer, and resource-constrained.

**Venezuela:** Venezuela’s disability inclusion mechanism has been pivotal in changing attitudes and practices towards disability inclusion. As a testament to its influence, disability considerations have been integrated into the 2022-23 Humanitarian Response Plan (HRP) and supported by Central Emergency Response Fund (CERF) funding. These shifts have led to tangible programmatic changes, such as the inclusion of children with disabilities in feeding projects, demonstrating the transformative potential of disability inclusion mechanisms.

These examples underpin the profound value-add of disability inclusion mechanisms in humanitarian responses. They bring to light the critical importance of actively involving persons with disabilities, advocating for policy change, and fostering resilience, thereby highlighting the need for disability inclusion to be central to all humanitarian action.

## Conclusion: Implications for future humanitarian responses

The case studies presented in this report – Afghanistan, Bangladesh, Ukraine, DRC, and Venezuela – offer compelling evidence of the value of such mechanisms contributing to the mainstreaming of disability in humanitarian or refugee needs assessments, response planning, or data collection by advocating for pivotal policy changes, and by fostering a climate of self-reliance and dignity. As revealed through these cases, these coordination mechanisms contributed to keeping the issue of disability inclusion on the agenda, and in the words of one cluster coordinator interviewed about the role of the ADTWG in Afghanistan, without working group being active, disability inclusion would revert to being a “tick box” exercise among humanitarian actors.

Strong leadership on disability inclusion by the Humanitarian Coordinator or sector/cluster coordinators are another ingredient necessary to accelerate the much needed operationalisation of the IASC Guidelines on disability inclusion at all levels of the humanitarian coordination to ensure timely and accountable, human centered response.

In conclusion, the insights gleaned from these case studies underscore the important role for better coordination of disability inclusion in humanitarian action. There is a pressing need to find a solution for how effective coordination of a complex technical issue that affects more than 15% of the population can happen in an increasing resource-constrained environment where humanitarian actors on the ground are pulled in many different directions simultaneously by competing priorities. This demands collective efforts from all stakeholders, including governments, international organizations, civil society, and most importantly, the affected communities themselves. Only by doing so can we progress towards a humanitarian ethos that upholds the rights, needs, and aspirations of all persons affected by crises, including those with disabilities.

# Appendices

## A. Themes for Case Study Investigation

### 1. Structure:

- What were the driving dynamics to arrive at structure/ particular setup, i.g. hosting arrangements (within cluster or not, why) which main governance tools? Changes over time?

### 2. Set-up

- What was the identified gap, need or push and by whom?) and when?
- Did these decisions have a foundation in a gap assessment and strategic approach towards DI coordination, informed by IASC GL or similar?

### 3. Scope, core-functions and identified success factors/challenges:

- What coordination, collaboration with protection and other clusters, and related AoRs, if any? (Protection monitoring, information sharing, CD, HPC influencing or?),
- Are focal points setup, how, on what, why?
  - What tools, products and/or results, if any were achieved by the mechanism in link with core-functions, incl. information sharing, advocacy, CD and/or monitoring DI in response and coordination? Are related processes and/or utilized tools to be recommended to other similar setups?
  - If in link/under the ICCG - what is the coordination, collaboration on? (MSNAs, HNO & HRP (across sectors), AAP, or?), are FPs setup, how, on what, why?
  - What is the link with the HPC and the HCT if any, and how is the relationship shaped?
  - What information hubs are utilized to share DI information?
  - What are successful processes and what are challenges felt? (for instance what gaps remain for what reasons?)

### 4. Leadership

- How is the leadership setup, understood and practiced?
- How are local actors engaged, incl. affected populations?
  - How is the engagement and meaningful participation of different members ensured and/or encouraged?

— What options for reasonable accommodation are available?

**5. What is the added value, if any, of specific DI coordination mechanism from perspective of members? What is the added value of a DI standalone mechanism versus having a wider inclusion (age, gender plus plus) mechanism?**

## B. List of interviewees

1. Afghanistan	
Godwin Kudzotsa	Disability and Inclusion Working Group Coordinator, HI Afghanistan Program
Billie Getachew Alemayehu	Humanitarian Affairs Officer, Strategy and Coordination Unit, OCHA
Daniel Hodges Mlenga	Food Security and Agriculture Cluster (FSAC) Coordinator, FAO
Marco Ferloni	FSAC Co-Coordinator, WFP
Hermann Ouedrago	Nutrition Cluster Coordinator, UNICEF
Zabihulla Habibi	Deputy Research Manager, Intersectoral, REACH
Karim Mirzad	Assessment Officer, REACH
Aamina Adham	Humanitarian Coordination Team, GenCap
Melissa Cornet	CARE International

2. Ukraine	
Nataliia Kondakova	Coordinator, Age and Disability Technical Working Group
Victoriia Panchenko	Former Coordinator, ADTWG
Claudia Nicoletti	Protection Cluster Coordinator, UNHCR
Oleksandra Makovska	Protection Cluster Coordinator
Tarryn Brown	Disability Inclusion Expert, Protection Cluster Ukraine & UNHCR Ukraine

### 3. Bangladesh

Shamanta Mostarin	Protection Associate, UNHCR
Johanna Reina Picalua	Information Management Associate, UNCHR
Liton Paul	Program Operation Manager, Center for Disability in Development
Shah M. Dedar	Disability Inclusion Coordinator, CBM Global
Humaira Mustary Mowry	Inclusion Technical Specialist, HI
Shiwendra Kumar	Inclusive Humanitarian Action Specialist, HI
Sadikur Rahman	Programme Policy Officer (Gender and Inclusion), WFP
Maria Afroze	Programme Assistant (Inclusion), WFP
Masum Billah	Past: Coordinator, Age & Disability Working Group (ADWG) Current: Protection Sector Coordinator, and Disability Inclusion Specialist from UNHCR
Marisa Maclennan	Inter Sector Coordination Officer, a.i. Principal Coordinator
Abu Naim Md. Shafiullah Talukder	Sector Support Officer
Mohita Joshi	GBV Sub Sector Information Management Coordinator
Tarrek Akkad	Child Protection Sector Coordinator, UNICEF

Age and Disability Working Group workshop, June 7, 2023

Participants from: BRAC, PHALS, BBC Media Action, NONGOR, WFP, ICRC, Help Cox's Basar, ISDE Bangladesh, WV Bangladesh, NGO Platform, START Fund Bangladesh, Upoma Nari Kalyan Sangstha, UTSA, Social Assistance and Rehabilitation for the Physically Vulnerable, Help Age International, Mukti Cox's Bazar

#### 4. Democratic Republic of the Congo

John Ntona	Founder, East Eagle Foundation
Arpana Pandey	Education Section Chief, UNICEF Kinshasa
Magaly Guevil	Inclusive Education focal point, Education Section, UNICEF Kinshasa
Gilberte Amari	Education Cluster Co-Coordinator, UNICEF
Hadissa Ouedragoo	Education Cluster Co-Coordinator, Save the Children
Luc Lusumba	Director, Congo Handicap

#### 5. Venezuela

Mariana Martinez	Inclusive Humanitarian Action Specialist, Humanity & Inclusion France
Yohanna Talloli	Especialista Regional en Acción Humanitaria Inclusiva, HI Venezuela
Juan Angel de Gouveia	Presidente, Confederación Sordos de Venezuela
Astrid Johana Mora Arias	Program Coordinator, Confederación Sordos de Venezuela
Patricia Bosco Leon	Protection Associate, Protection Cluster, UNHCR

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## Lessons learned

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# Mechanisms for Coordination of Disability Inclusion in Humanitarian Action

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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.

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