



Wide angle

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# Global Mapping of Disability Inclusion Coordination Mechanisms in Humanitarian Contexts

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October 2023

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and the “From Guidelines to Action” project

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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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## Acronyms and Specialized Terms

|                |   |
|----------------|---|
| <b>AAP</b>     | Accountability to Affected Populations  |
| <b>AOR</b>     | Area of Responsibility (under the Protection Cluster several AORs focus on different aspects of protection, for example Child Protection) |
| <b>CBM</b>     | Christoffel-Blindenmission (originally, now simply CBM)   |
| <b>CCCM</b>    | Camp Coordination and Camp Management   |
| <b>DI</b>      | Disability inclusion  |
| <b>DIWG</b>    | Disability Inclusion Working Group  |
| <b>DRC</b>     | Democratic Republic of the Congo  |
| <b>FP</b>      | Focal Point   |
| <b>GBV</b>     | Gender-Based Violence   |
| <b>GenCap</b>  | Gender Standby Capacity Project   |
| <b>HCT</b>     | Humanitarian Country Team   |
| <b>HNO</b>     | Humanitarian Needs Overview   |
| <b>HPC</b>     | Humanitarian Program Cycle  |
| <b>HRP</b>     | Humanitarian Response Plan  |
| <b>IASC GL</b> | Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action (IASC, 2019)  |
| <b>ICCG</b>    | Inter-Committee Coordination Group  |
| <b>MHPSS</b>   | Mental Health and Psychosocial Support  |
| <b>MSNAs</b>   | Multi-Sector Needs Assessments  |
| <b>OCHA</b>    | United Nations Office for the Coordination of Humanitarian Affairs  |
| <b>OPDs</b>    | Organizations of Persons with Disabilities  |
| <b>ProCap</b>  | Protection Standby Capacity Project   |
| <b>PSEA</b>    | Protection from Sexual Exploitation and Abuse   |
| <b>UN</b>      | United Nations  |

## Acronyms and Specialized Terms

|               |   |
|---------------|---|
| <b>UNCT</b>   | United Nations Country Team                   |
| <b>UNDIS</b>  | United Nations Disability Inclusion Strategy  |
| <b>UNHCR</b>  | United Nations High Commissioner for Refugees |
| <b>UNICEF</b> | United Nations Children's Fund                |
| <b>TF</b>     | Task Force                                    |
| <b>TORs</b>   | Terms of References                           |
| <b>WASH</b>   | Water, Sanitation, and Hygiene                |
| <b>WG</b>     | Working Group                                 |

## Summary

The purpose of this mapping exercise was two-fold: (1) to pull-together and aggregate information about disability inclusion coordination approaches from many different sources; and (2) to produce recommendations about which of these different mechanisms might yield further lessons learned if developed further into case studies.

This global mapping exercise was undertaken in December 2022 and January 2023.

The mapping exercise found evidence of active disability inclusion coordination mechanisms in only 12 (39%) of the 31 humanitarian contexts it reviewed. In another 6 cases, previous surveys had reported that one had existed in the past but had become dormant.

## Methodology

The sampling frame in this mapping included 31 humanitarian situations, including the 28 countries for which Humanitarian Response Plans were prepared in 2022 plus Jordan, North West of Syria and Uganda where Humanity and Inclusion had an on-going operational presence. The mapping considered only two countries covered by a refugee response plan, Bangladesh and Uganda.

Drawing on previous mapping exercises, the internet platform [humanitarianresponse.info](https://humanitarianresponse.info), references from global experts and OCHA's 2021 survey of coordination structures, the mapping determined that 17 of the 28 countries had some evidence of a disability-related coordination mechanism at one point in time. In six of these cases, after follow-up, no evidence of current active disability coordination structures could be determined. See Table 1.

**Table 1 Where disability-related coordination mechanisms were found**

| Country                  | No Evidence | OPD Membership | OPD Leadership |
|--------------------------|-------------|----------------|----------------|
| Afghanistan (1)          |             |                | X              |
| Bangladesh               |             | X              |                |
| Burundi                  | X           |                |                |
| Burkina Faso             | X           |                |                |
| Central African Republic | X           |                |                |
| Cameroon                 | X           |                |                |
| Chad                     | X           |                |                |

| Country                        | No Evidence | OPD Membership | OPD Leadership |
|--------------------------------|-------------|----------------|----------------|
| Columbia                       | X           |                |                |
| Democratic Republic of Congo   |             |                | X              |
| El Salvador                    | X           |                |                |
| Ethiopia                       | X           |                |                |
| Guatemala                      | X           |                |                |
| Honduras                       | X           |                |                |
| Haiti                          | X           |                |                |
| Iraq                           | X           |                |                |
| Jordan                         |             | X              |                |
| Libya                          | X           |                |                |
| Mali                           | X           |                |                |
| Myanmar                        |             | X              |                |
| Mozambique                     | X           |                |                |
| Niger                          | X           |                |                |
| Nigeria                        | X           |                |                |
| occupied Palestinian territory | X           |                |                |
| Somalia                        | X           |                |                |
| South Sudan                    | X           |                |                |
| Sudan                          | X           |                |                |
| North West Syria               |             | X              |                |
| Uganda                         |             | X              |                |
| Ukraine                        |             | X              |                |
| Venezuela                      |             |                | X              |
| Yemen                          |             | X              |                |
| Total                          | 22          | 7              | 3              |

Note:

(1) An OPD is not currently involved in the co-Chairing of the coordination group, however the Accessibility Organization for Afghan Disabled, an Afghan OPD, was an active participant member of the Humanitarian Country Team in 2020, prior to the Disability Inclusion Working Group being established. There are current discussions to structure the leadership of the current DIWG in the future to include an INGO, a UN entity and an OPD.

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

# 1. Background

The inclusion of persons with disability in humanitarian responses is recognized as an urgent need, yet within 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, the capacity of actors, and the quality of programming.

The aim of the assignment is to understand more comprehensively and systematically how issues related to disability inclusion are expressed in emergency response settings via different forms of coordination. The project will have two stages: the initial mapping, followed by a more detailed analysis of a selected number of coordination structures.

This mapping systematically describes the types of coordination mechanisms that exist at the field level, their roles, capacities and resources.

## 2. Disability Coordination Mechanisms

Disability coordination mechanisms call themselves many different things, the most common being “Working Groups” (or Sub-Working Groups in the case of refugee response contexts) in about half the cases investigated. Four in the sample appended “technical” to Working Group. We also found networks, Task Forces and one in Burkina Faso called a Framework for Coordination of International NGOs working in the field of disability (“Cadre de Coordination des ONG Internationales intervenant dans le domaine du Handicap”) a group that has since gone off-line.

Whatever they call themselves, most groups that could recall when they started have only been in place for one or two years. The longest-lived structure, an inclusive education network in the Democratic Republic of the Congo, began in 2011, but is primarily concerned with inclusive education more broadly and not specifically with inclusive education in emergencies. The Age and Disability Technical Working Group in Ukraine was established just after the Russian occupation of the Crimea in 2015 when it quickly grew but almost disappeared when its host Protection Cluster was poised to deactivate in late 2021, but has again become very active following the full-scale invasion in February 2022.

Typically, disability inclusion groups meet monthly, although key organizers may meet more frequently on an *ad hoc* basis as the situation requires. In one case, the group meets only annually, but it was determined that this coordination mechanism (in Iraq) was set up only to compile the Disability Inclusion Strategy UN Country Team annual accountability report card, and so it not related to on-going support to humanitarian action.

### 3. Resourcing

Most groups are unfunded. In four cases where funding is available to support the costs of a group coordinator, these funds were provided by a disability inclusion focused INGO (Humanity & Inclusion, HelpAge, CBM). One of these organizations reports that this process requires repeated fundraising efforts in order to ensure continuity and the continued existence of the group they are supporting. As is typical in humanitarian action, funding tends to be very short-term typically annually.

Typically, when an organization suggests a workplan action, for example a training program, it also commits to funding it: “what you propose, you pay for”.

In several cases NGO supporters and donors have also provided short-term deployments to provide additional technical assistance to improving disability inclusion in humanitarian responses, such as in Syria or Ukraine.

Any administrative or office support to the coordination structure for example to host meetings, or maintain mailing lists to distribute minutes, is donated. In several cases this support is provided by the Protection Cluster coordinator’s office, or by UN OCHA in the two cases where the coordination structure falls under the Inter-Cluster Coordination Group.

### 4. Membership

Most groups where membership could be defined were broadly inclusive with membership open to any operational entity with an interest in disability inclusive programming. In one case (Ukraine) almost 300 addresses are on the current newsletter mailing list, including a very large number of Ukrainian Organizations of Persons with Disabilities (OPDs). In another case (the inclusive education network in DRC) only local OPDs are members. Table 2 presents an analysis of OPD participation across the sample countries. Actual engagement is generally much narrower, with typically far fewer than 20 participants taking part in meetings.

**Table 2 Organizations of Persons with Disabilities participation in coordination structures**

| Country                  | No Evidence | OPD Membership | OPD Leadership |
|--------------------------|-------------|----------------|----------------|
| Afghanistan (1)          |             |                | X              |
| Bangladesh               |             | X              |                |
| Burundi                  | X           |                |                |
| Burkina Faso             | X           |                |                |
| Central African Republic | X           |                |                |
| Cameroon                 | X           |                |                |
| Chad                     | X           |                |                |

| Country                        | No Evidence | OPD Membership | OPD Leadership |
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| Columbia                       | X           |                |                |
| Democratic Republic of Congo   |             |                | X              |
| El Salvador                    | X           |                |                |
| Ethiopia                       | X           |                |                |
| Guatemala                      | X           |                |                |
| Honduras                       | X           |                |                |
| Haiti                          | X           |                |                |
| Iraq                           | X           |                |                |
| Jordan                         |             | X              |                |
| Libya                          | X           |                |                |
| Mali                           | X           |                |                |
| Myanmar                        |             | X              |                |
| Mozambique                     | X           |                |                |
| Niger                          | X           |                |                |
| Nigeria                        | X           |                |                |
| occupied Palestinian territory | X           |                |                |
| Somalia                        | X           |                |                |
| South Sudan                    | X           |                |                |
| Sudan                          | X           |                |                |
| North West Syria               |             | X              |                |
| Uganda                         |             | X              |                |
| Ukraine                        |             | X              |                |
| Venezuela                      |             |                | X              |
| Yemen                          |             | X              |                |
| Total                          | 22          | 7              | 3              |

Note:

(1) An OPD is not currently involved in the co-Chairing of the coordination group, however the Accessibility Organization for Afghan Disabled, an Afghan OPD, was an active participant member of the Humanitarian Country Team in 2020, prior to the Disability Inclusion Working Group being established. There are current discussions to structure the leadership of the current DIWG in the future to include an INGO, a UN entity and an OPD.

Key informants pointed to the high staff turnover in humanitarian situations impacting membership and participation in coordination mechanisms. This may be an explanation for why earlier mapping exercises identified coordination structures that may now no longer exist.

Active participation in coordination groups seems in some cases to be driven by funding opportunities rather than an interest in improving the quality of programming for the humanitarian system as a whole. This is understandable considering the small size and resource constraints among operational humanitarian actors and OPDs.

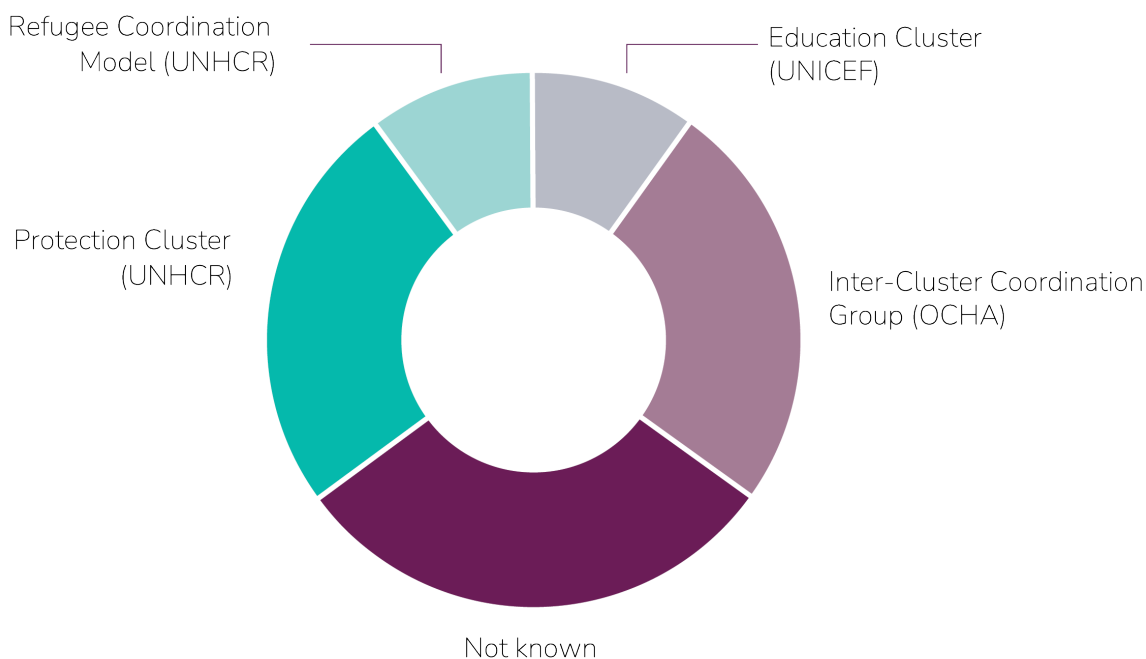
## 5. Hosting Structure / Affiliation / Chair or Co-Chair

Humanity & Inclusion Chairs or Co-Chairs over 40% of the disability coordination mechanisms that were identified.

Disability inclusion coordination mechanisms are frequently hosted by the Protection Cluster, which treats disability inclusion as a cross-cutting topic similar to gender, sexual and gender-based violence or accountability to affected populations. Where the response is a refugee situation, as in Bangladesh or Uganda in this sample, the UNHCR's Refugee Coordination Model applies. In other humanitarian responses such as Ukraine, Venezuela, North West Syria, where disability inclusion is hosted by the Protection Cluster, UNHCR applies the cluster coordination model.

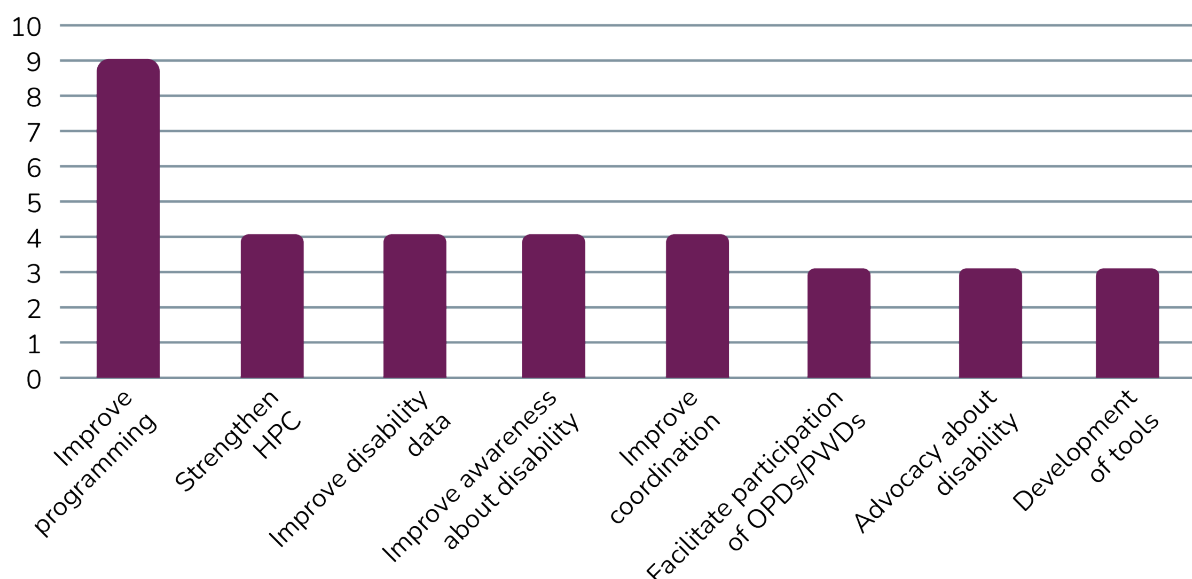
Two coordination structures are linked in some way to the Education Cluster (in the Central African Republic and Niger) while coordination structures in Afghanistan, Jordan, Myanmar and Yemen work through the Inter-Cluster Coordination Group (ICCG) in those countries. Myanmar actually has two disability coordination structures, a national Technical Advisory Group hosted by OCHA working through the ICCG and a second more operational group in the area of WASH supported by UNICEF and Humanity & Inclusion.

### Host for Disability Inclusion Coordination Structures



## 6. Objectives

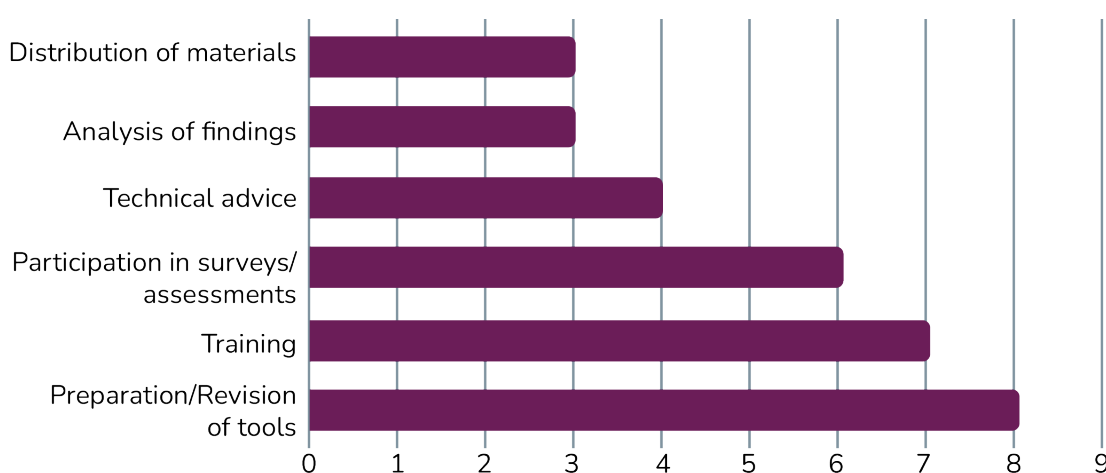
There is no standard template of objectives among the different coordination mechanisms, in the cases where this could be systematically analyzed by referring to a Terms of Reference or where it was raised during a key informant interview. Generally, these mechanisms exist to share experiences towards improving disability inclusive programming. Only four coordination mechanisms referenced strengthening disability inclusion in Humanitarian Program Cycle processes as an objective.



## 7. Activities

As one group participant put it, activities are “very dependent on the energy of the members to move things forward”. Several mentioned how the initiatives on the agenda of a particular organization *de facto* become the activities undertaken by the coordination group, as funding was so limited.

### Activities



## 8. Collaborators

Disability inclusion coordination structures in humanitarian response situations work alongside many other types of groups, such as humanitarian Clusters, Sub-Clusters, Areas of Responsibility, Sectors, Inter-Agency groups, Task Forces and Working Groups. Rarely did the disability inclusion coordination structure have a formalized role in the humanitarian programme cycle. The proliferation of different interest groups makes it difficult to sustain attention, and for this reason disability inclusion coordination groups collaborate with other groups or organizations to advance progress on a process or activity.

Most frequently mentioned were the connections these groups made with implementors in particular sectors on specific operational topics, such as supporting a UN agency to collect improved data. Next most frequent mention was the observation that their host Cluster (Education or Protection) was the closest collaborator. Because their working approaches were similar, working groups or sub-clusters promoting the cross-cutting areas of Gender in Humanitarian Action, Accountability to Affected Persons, and Gender-based Violence were mentioned as natural allies in contexts where these exist.

## 9. Structure and formalized workflow

About 40% of the identified coordination structures described a formalization of the group in terms of a clear organizational structure or common work plan, typically when a Terms of Reference exists for the group.

Funded personnel dedicated to disability inclusion coordination is extremely rare. As an example, in Afghanistan, the position of Coordinator for the Disability Inclusion Working Group is funded as part of a short-term humanitarian Humanity & Inclusion project. In other cases, part-time coordination work is carried out by the INGO Country Office staff as another of their many duties. This tenuous funding situation raises continuity issues.

It was assumed that a standard approach to disability inclusion coordination would be where different humanitarian actors designated focal points. This seems to actually be quite rare. Asked about focal points, respondents commonly pointed out that this approach was difficult. In humanitarian situations there is often a high turnover of staff, and members come and go. Few organizations are serious about ensuring the stable participation of their focal point, where these exist. The difficulty of calibrating the seniority of participation was mentioned as an issue particularly in relation to UN staff participation.

## 10. Links to Humanitarian Program Cycle Processes

Only about a third of the coordination structures that were reviewed indicated a link to the Humanitarian Program Cycle (HPC), such as work to support the Humanitarian Needs Overview process, for example through assessment survey training or technical support to disability disaggregated data analysis.

Due to its formal link to the Protection Sector in Uganda, the Persons with Specific Needs Sub-Working Group in Uganda does have a formal link to the refugee response plan: it has an indicator in the multi-year plan for which it is responsible.

## 11. Governance

40% of coordination structures have Terms of References more relatively stable governance processes. TORs commonly define how the group works, who can participate, and how the Chair (and sometimes Co-Chair roles) are assigned.

In a few cases (Afghanistan, Bangladesh, Venezuela) respondents described an intentionally diverse leadership, where a UN agency shared responsibility with an INGO and a local organization, ideally an organization of persons with disabilities.

In one case (Ukraine) no leadership succession process was specified in the TOR and this is currently causing tension.

## 12. Main Gaps

Disability coordination structures are quite rare in humanitarian response, and where they exist, they are quite volatile, emerging and then disappearing based on short funding cycles. Coordination structures are not fit into the humanitarian response architecture in any standard manner. Organizations of persons with disability participate in these coordination structures in only a minority of cases and are very rarely in a leadership function. Systematic engagement in humanitarian program cycle processes, such as needs assessments or in the formulation of humanitarian response plans is unusual.

## 13. Recommended Case Studies

In order to “unpack” the nature of these gaps and to learn more about the experiences of existing disability coordination structures a series of case studies is proposed. Four key criteria were proposed for reviewing the identified coordination structures and identifying 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 for consideration:

| Country   | Richness of Information   | Diversity of Approaches  | Audience Interest   | Results Achieved  |
|---|---|--|---|---|
| <b>Ukraine</b><br>Age and Disability Technical Working Group                                  | Full-time Coordinator (HelpAge) plus disability technical advisors on surge                 | 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, so long history. Abundance of tools, broadly inclusive                                   |
| <b>Venezuela</b><br>Grupo de Trabajo Sobre Edad y Discapacidad en la Acción Humanitaria       | Humanity & Inclusion advisors   | 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 |
| <b>Democratic Republic of the Congo</b><br>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><br>Disability Inclusion Working Group                                      | Full-time coordinator, Co-Chairs of Working Group, REACH, Allied cross-cutting groups       | 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><br>Age and Disability Working Group   | Dedicated national Coordinator, strong partnership base                                     | Refugee response. Sub-Working Group of Protection Sector   | Protracted refugee response   | Reform of the registration update process to include disability disaggregated data                            |

# Annex 1: Mapping Research Questions

1. **Type of mechanism:** Working Group (WG), Task Force (TF), Focal Point (FP) in the cluster, other.
2. **Duration of existence & frequency of meetings.**
3. **Resourcing:** funding type, funding amounts, funding duration, dedicated staff, coordination & administrative capacities?
4. **Membership:** national, international, organisations of persons with disabilities, UN agencies, line-ministries, other.
5. **Hosting structure:** which cluster, sector or inter-sector working group, if any, as part of the ICCG, or other?
6. **Main priorities & specific outcomes:** Capacity development & training, advocacy, evidence & data, coordination around disability inclusion reaching other sectors and Humanitarian Program Cycle (HPC) processes, including; Protection from Sexual Exploitation and Abuse (PSEA), Accountability to Affected Populations (AAP); are the mechanisms only focussing on disability or on other cross-cutting themes, such as AAP, Gender, Age, minorities and indigenous peoples, gender identity too.
7. **Main type of engagements:** typical activities and sphere of influence at what level (capacity development, Advocacy, Evidence & Data, Coordination around DI reaching other sectors and/or HPC processes, technical support, incl. PSEA, AAP, Meaningful Participation of OPDs/ Organizations of Persons of old Ages (OPA) or similar) or products such as briefs, guidance, contribution to HPC or Multi-Sector Needs Assessments (MSNAs), policy changes, advocacy campaign, common training tools or guidance changes.
8. **Main collaborators:** Clusters/AoRs/Sectoral working groups (protection, CP AoR, GBV AoR, Health, CCCM, etc.) or WGs (Data and Information Management, COVID, AAP, PSEA or) or ProCap, GenCap, or Surge Capacities (if yes, on what: coordination, advocacy, data, Meaningful Participation, CD); are the mechanisms connecting with other mechanisms/ WGs working towards cross-cutting themes such as MHPSS, Gender, Minority Clan, Age, etc.? (if yes, frequency... and themes of collaboration: coordination, advocacy, data, Meaningful Participation, CD).
9. **Structural setup:** Focal point system in place for either sectorial/ Cluster engagements or cross-cutting topic focus or not.
10. **Level of formalization** (annual action planning, in alignment with other sectorial and/or HNO & HRP).
11. **Chairing or Co-chairing** organizations.

**12. Provision of reasonable accommodation** to current or future members.

**13. Governance:** Terms of Reference, MoU with line-ministries / other?

**14. Contact Details:** Coordinator (Chair), and Co-chair?

## Annex 2: Case Study Collection Research Questions

- **Structure:** (working group, task force, individual focal points in the cluster) what are / were the needs / demands / dynamics / gaps identified that led to the chosen structure / setup? Does the group's establishment have a foundation in a gap assessment and strategic approach towards DI coordination, informed by IASC GL, led by whom, HCT, Gov't, NGO, Civil society. Hosting arrangements (within the cluster, a single agency leading, government, other. What are the main governance arrangements are these effective? Any changes over time? 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?
- **Core-functions and identified success factors / challenges:**
  - What (notable / regular) outputs and results have been achieved through the coordination mechanism to-date including: information sharing & awareness raising, advocacy, training and capacity development of partners, coordination, funding allocation, needs assessment, data collection / research and monitoring. Are related processes and / or utilized tools to be recommended for other mechanisms?
  - If linked or failing under remit of the ICCG - what is the coordination, collaboration on? (MSNAs, HNO & HRP (across sectors), AAP, or others), are there focal points appointed, what is their role and responsibility, how were they set-up and why?
  - What is the link with the HPC and the HCT if any, and how is the relationship shaped?
  - How the coordination structure has linked with / supported rapid onset emergency response efforts in the past: assessment support, advisory etc.
  - What information management mechanisms are in place to share disability specific data, information?
  - What are the current gaps and limitations in the coordination structure, what could be done to strengthen and overcome?
  - What are some key successful outcomes and results?

● **Leadership and membership:**

- How is the leadership setup, understood and practiced? How are local actors engaged, incl. affected populations, organisations of people with disabilities?
- How is the engagement and meaningful participation of different members ensured and / or encouraged?
- What options for reasonable accommodation are available?

● **Added Value**

- What is the benefit of disability specific coordination mechanisms from perspective of members? What is the benefit of a disability specific mechanism versus having a wider inclusion (age, gender plus plus) mechanism?



## Wide angle

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The purpose of this mapping exercise was two-fold: (1) to pull-together and aggregate information about disability inclusion coordination approaches from many different sources; and (2) to produce recommendations about which of these different mechanisms might yield further lessons learned if developed further into case studies.

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The mapping exercise found evidence of active disability inclusion coordination mechanisms in only 12 (39%) of the 31 humanitarian contexts it reviewed. In another 6 cases, previous surveys had reported that one had existed in the past but had become dormant.

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