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Mainstreaming Disability in Humanitarian Action

A Field Study from Cox's Bazar,
Bangladesh

Carolin Funke and Dennis Dijkzeul





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To safeguard academic standards, the authors of this paper, Carolin Funke and Dennis Dijkzeul, have carried out this study independently. They are solely responsible for the contents of this report.

Contents

List of Acronyms	10
Executive Summary	13
1. Introduction	19
1.1 International Background	19
1.2 Local Background	22
1.3 Purpose and Key Research Questions	24
1.4 Relevance	24
1.5 Report Structure	25
2. Methodology	27
2.1 Case Selection	27
2.2 Data-collection Methods	28
2.3 Data-analysis Methods	30
2.4 Limitations	30
3. Contextual Overview: Persons with Disabilities in the Camps and Host Communities	33
3.1 Situation in the Camps	34
3.2 Refugees with Disabilities: Perceptions and Barriers	35
3.3 Situation in the Host Communities	40
3.4 Persons with Disabilities in the Host Communities: Perceptions and Barriers	41
3.5 Conclusion	43

4. Disability Inclusion in Humanitarian Action: Partnerships and Consortia	45
4.1 Donor-recipient Partnerships: United Nations Agencies and Disability-focused Non-governmental Organizations	47
4.2 Non-governmental Organization Consortia	48
4.3 Age and Disability Working Group	49
4.4 Partnerships, Consortia and the Age and Disability Working Group: Approaches to Disability Inclusion	50
4.4.1 United Nations Agencies and Donor-recipient Partnerships	50
4.4.2 Non-governmental Organizations and Consortia Projects	59
4.4.2.1 Donor Funding	61
4.4.2.2 Administrative Procedures and Internal Organizational Processes	64
4.4.3 Age and Disability Working Group	71
5. Conclusions	77
5.1 Main Findings	77
5.2 Recommendations	80
5.2.1 Donors	80
5.2.2 Bangladeshi Authorities	81
5.2.3 International Humanitarian Organizations	81
5.2.4 National and Local Non-governmental Organizations	84
5.2.5 Persons with Disabilities	84
5.2.6 Further Research	84
Bibliography	87

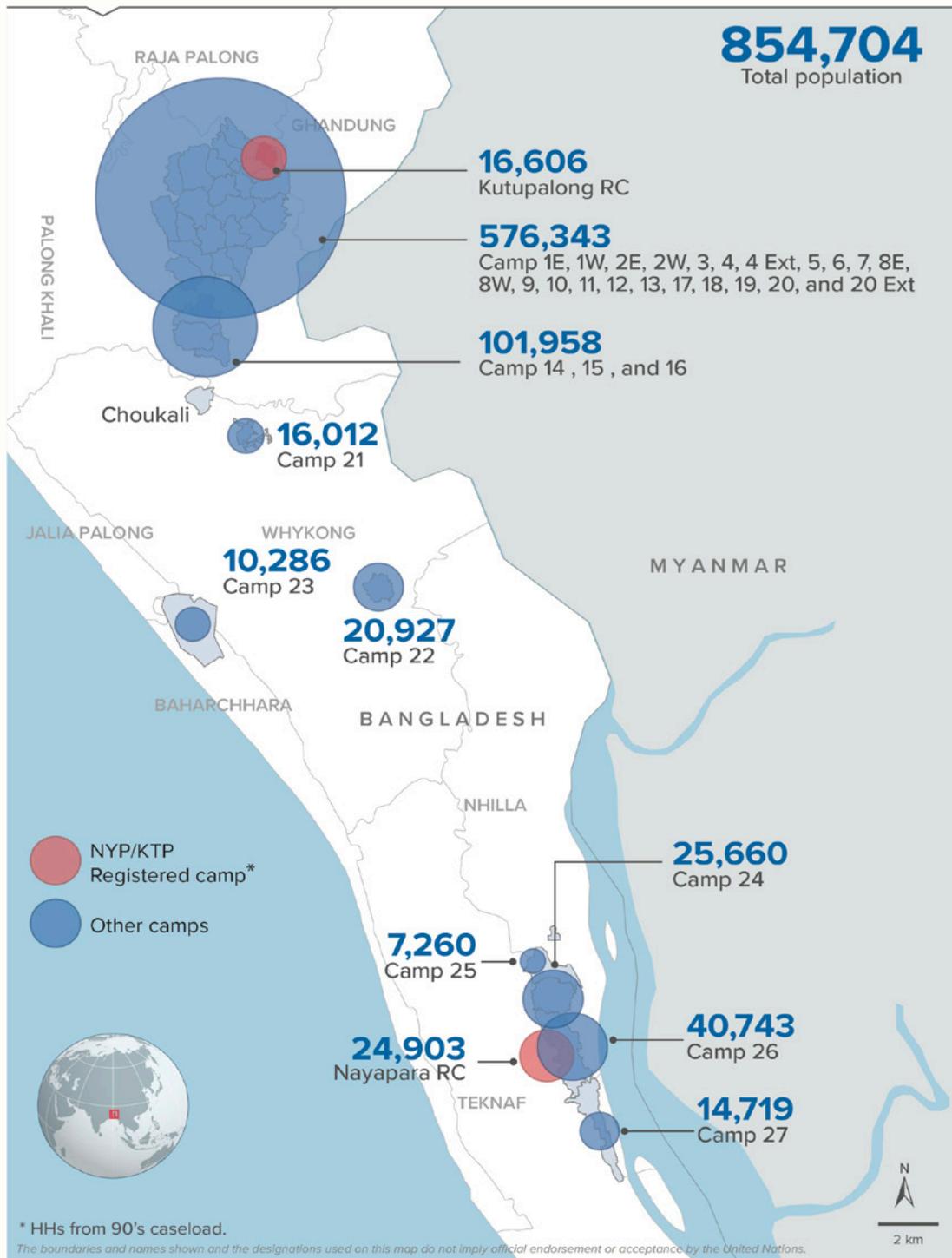
List of Boxes

Box 1.	Tasmin: Targeted Assistance to Persons with Disabilities to Foster their Inclusion in the Camps	38
Box 2.	Washington Group Questions	39
Box 3.	Nadim: Inclusion in the Host Community	42
Box 4.	The Configuration of the Humanitarian Coordination Structure	56
Box 5.	The Government of Bangladesh and the Rohingya Response	69
Box 6.	Development of the Age and Disability Working Group	74

List of Maps

Map 1.	Number of Registered Refugees, 31 January 2021	8
Map 2.	Cox's Bazar Camp Locations	9

Map 1.
Number of Registered Refugees, 31 January 2021



Source: Government of Bangladesh and United Nations High Commissioner for Refugees (UNHCR) (2019).

Map 2.
Cox's Bazar Camp Locations



Source: Inter-Sector Coordination Group (ISCG) (2020).

List of Acronyms

ADCAP	Age and Disability Capacity Programme
ADWG	Age and Disability Working Group
CBM	Christian Blind Mission International
CDD	Centre for Disability in Development
CiC	Camps-in-Charge
CRPD	Convention on the Rights of Persons with Disabilities
DFAT	Department of Foreign Affairs and Trade of Australia
DFID	Department for International Development of the United Kingdom
ECHO	European Civil Protection and Humanitarian Aid Operations
EU	European Union
HI	Handicap International – Humanity & Inclusion
HIES	Household Income and Expenditure Survey
IASC	Inter-Agency Standing Committee
IDA	International Disability Alliance
INGO	International non-governmental organization
IOM	International Organization for Migration

ISCG	Inter-Sector Coordination Group
NGO	Non-governmental organization
NNGO	National non-governmental organization
OCHA	United Nations Office for the Coordination of Humanitarian Affairs
OPD	Organization of persons with disabilities
RC	Registered camp
RRRC	Office of the Refugee Relief and Repatriation Commissioner
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
WASH	Water, sanitation and hygiene
WHO	World Health Organization



Executive Summary

Disability inclusion is crucial to effective humanitarian action. Since the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), disability has been firmly established as a human rights issue and key donors make it a prerequisite for funding. Many humanitarian organizations have also committed themselves to including persons with disabilities in their work in line with the core humanitarian principles of humanity, impartiality, neutrality and independence (for example, by signing the Charter on Inclusion of Persons with Disabilities in Humanitarian Action). In daily practice, however, the protection of the rights of persons with disabilities is still lagging behind.

In Cox's Bazar, Bangladesh, more than 870,000 refugees have found shelter after fleeing from Myanmar. While all of them live in dire conditions, persons with disabilities face even more severe barriers in accessing humanitarian services and participating in the humanitarian response. To ensure the inclusion and protection of persons with disabilities, humanitarian actors have been increasingly reaching out to disability-focused organizations for technical support and capacity-building. Some organizations have also entered into strategic partnerships or formed consortia projects with disability-focused organizations to systematically build up their capacities on inclusion. Three disability-focused organizations (Humanity & Inclusion (HI), Christian Blind Mission (CBM) and the Centre for Disability in Development (CDD)) and HelpAge International established the Age and Disability Working Group (ADWG) to promote the inclusion of older persons and persons with disabilities within the wider humanitarian response by providing technical support to the coordination mechanism (clusters). Despite these efforts, the inclusion of persons with disabilities remains an ongoing challenge.

Research in Cox's Bazar demonstrates that many organizations have only just started to build their capacity and thus lack expertise on how to ensure the inclusion of persons with disabilities throughout their programmes. Despite some level of commitment from numerous humanitarian actors, as evidenced though their signing of the Charter on Inclusion of Persons with Disabilities in Humanitarian Action, a systematic approach to ensuring the inclusion of persons

with disabilities in their organizations, programmes and services is still lacking. In fact, the inclusion of persons with disabilities most often depends on the initiatives and motivations of a few individuals within the organizations. Moreover, there are still insufficient financial resources allocated to inclusive humanitarian action. This is a problem in Cox's Bazar, where humanitarian actors require considerable resources to address past failures in the planning and construction of the camp's infrastructure. To make services accessible for everyone, roads, facilities and shelters must be remodelled. Yet short funding cycles, frequent staff turnover and administrative procedures that entail a high workload for humanitarian staff reduce the time and resources needed to create an inclusive environment and ensure the meaningful participation of persons with disabilities. These issues take away time that could be spent on building the capacity of humanitarian staff.

To ensure the inclusion of persons with disabilities, it is crucial that donors guarantee sustainable and reliable funding. This will allow organizations to focus on capacity-building and make the necessary investments to build an accessible environment. Humanitarian actors should promote the meaningful participation of persons with disabilities, collect, analyse, use and share data disaggregated by age, gender and disability, reduce attitudinal, environmental and institutional barriers, identify good practices and learn from one another's experiences. Ideally, the Government of Bangladesh and humanitarian actors will facilitate longer-term programming to contribute to the inclusion of persons with disabilities in humanitarian services until a return of the Rohingya to Myanmar becomes possible (see Reliefweb, 2020).

For future humanitarian crises, it is crucial that more attention is directed towards capacity-building at the headquarters level of humanitarian organizations. Disability inclusion is a strategic issue for the whole organization, and headquarters therefore need to promote a policy on age, gender and diversity in all operations. This will enhance equality, foster non-discrimination and ensure the systematic incorporation of persons with disabilities in humanitarian activities at all stages of the humanitarian response (preparedness, response and recovery).

Key Points

- Persons with disabilities face many barriers in accessing humanitarian services.
- During the immediate Rohingya crisis response in 2017 and 2018, humanitarian actors did not consider the rights and specific requirements of persons with disabilities.
- The camps' infrastructure has been developed in such a way that persons with disabilities face many barriers and cannot easily benefit from the humanitarian response.
- Humanitarian actors recognize the need to reduce attitudinal, environmental and institutional barriers and are striving to become more inclusive in their work.
- Humanitarian actors are increasingly reaching out and collaborating with disability-focused organizations and establishing formal partnerships and consortia. Nevertheless, the actual inclusion of persons with disabilities remains an ongoing challenge as they often continue to be excluded and left behind.
- **Donors** have short funding cycles, which prevent long-term planning and activities. Reliable and flexible funding are crucial for successful disability mainstreaming.
- Relaxation of approval requirements by the relevant government **authorities** will enable humanitarian actors to spend more time on capacity-building and technical support.
- **International humanitarian organizations** lack the capacity to mainstream disability into their programmes. Building internal capacity at headquarters, the programme level and in the field and developing and closely monitoring the implementation of long-term strategies and action plans reduces the risk of the inclusion of persons with disabilities remaining in the hands of only a few individuals.

- **National and local non-governmental organizations (NGOs)** make a vital contribution to the humanitarian response, but as is the case with international organizations, need to build their capacities on disability mainstreaming and gradually assume a leading role in the response.
- The work of **disability-focused NGOs** in providing targeted assistance to persons with disabilities and in building the capacity of various humanitarian partner organizations to include persons with disabilities remains key to protecting their rights and enabling their participation in the humanitarian response.
- **Persons with disabilities** need to become familiar with their rights and be empowered to speak up for themselves. In the host communities they have the right to form organizations of persons with disabilities (OPDs). In the camps, persons with disabilities sometimes form informal disability committees. Organizations should encourage the formation of more informal groups and strengthen their capacity to meaningfully participate and contribute to matters of their concern inside the camps. Enjoying their right to form OPDs would enable persons with disabilities to specify their preferred ways of inclusion.
- The **ADWG** is an initiative of HI, CBM, CDD and HelpAge International. Thanks to collaboration with the protection sector, the ADWG strongly contributes to age and disability inclusion in the humanitarian response. A joint registration exercise with the United Nations High Commissioner for Refugees (UNHCR) and the REACH Initiative will be a first step in closing important data gaps and enhancing the visibility of persons with disabilities. However, sustained advocacy of their human rights in different clusters and capacity-building on inclusion remain necessary to support long-term change.
- Strategic partnerships and consortia projects with **disability-focused NGOs** are evaluated positively in this study but their overall long-term impact is still hard to assess.

- Disability-inclusive humanitarian action is an under-researched topic. More long-term ethnographic and impact studies as well as a comprehensive review of the compliance with and implementation of international normative instruments on the inclusion of persons with disabilities are necessary to better inform daily practice.

Key Words

Inclusive humanitarian action;

disability mainstreaming;

Rohingya refugee crisis;

partnerships and consortia;

ethnographic disability research



1. Introduction

1.1 International Background

Since the United Nations Convention on the Rights of Persons with Disabilities (CRPD) entered into force in May 2008, numerous policy tools and guidelines have been produced at the global level to support the inclusion of persons with disabilities in humanitarian action. The most relevant are the **Charter on Inclusion of Persons with Disabilities in Humanitarian Action** (2016), the **Humanitarian Inclusion Standards for Older People and People with Disabilities** (2018) and the Inter-Agency Standing Committee (IASC) **Guidelines on Inclusion of Persons with Disabilities in Humanitarian Actions** (2019).¹

At the 2016 World Humanitarian Summit in Istanbul, states, United Nations agencies and non-governmental organizations (NGOs) reaffirmed their responsibility towards persons with disabilities in humanitarian action and launched the Charter on Inclusion of Persons with Disabilities in Humanitarian Action. By 2020, more than 200 actors had signed the Charter and pledged to:

1. Condemn and eliminate all forms of discrimination against persons with disabilities in humanitarian programming and policy;
2. Promote meaningful involvement of persons with disabilities and their representative organizations in humanitarian preparedness and response programmes;
3. Ensure protection for persons with disabilities as required by international law;

¹ The IASC is the highest-level humanitarian coordination forum. It comprises 18 United Nations and non-United Nations agencies to ensure sound preparedness and response efforts. For more information, see the [Inter-Agency Standing Committee website](#).

4. Ensure that services and humanitarian assistance are equally available for and accessible to all persons with disabilities; and
5. Foster technical cooperation and coordination among national and local authorities and all humanitarian actors. Actors have also embraced the development of international high-quality guidelines, which provide support to improve the inclusion of persons with disabilities in emergency preparedness and responses (Christian Blind Mission [CBM] and Humanity & Inclusion [HI], 2020).

In 2018, the Age and Disability Capacity Programme (ADCAP) developed the Humanitarian Inclusion Standards for Older People and People with Disabilities. These standards seek to strengthen the accountability of humanitarian actors to older people and persons with disabilities and serve as a guide for programming and a resource for training and advocacy. More than 300 stakeholders from organizations of persons with disabilities (OPDs), older people's associations and humanitarian organizations worldwide provided inputs for the development of these standards, which comprise nine key inclusion standards and seven sets of sector-specific inclusion standards. These are:

1. protection;
2. water, sanitation and hygiene (WASH);
3. food security and livelihoods;
4. nutrition;
5. shelter, settlement and household items;
6. health; and
7. education.

Each standard has its own key actions, guidance, tools and resources (Age and Disability Capacity Programme [ADCAP], 2018).

One year later, in 2019, the IASC endorsed the Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action. The development of these guidelines was led by the IASC Task Team, which was co-chaired by Humanity & Inclusion (HI), the United Nations Children’s Fund (UNICEF) and the International Disability Alliance (IDA). The guidelines reflect the input of more than 600 stakeholders across disability, development and humanitarian sectors and set out essential actions that humanitarian actors must take to identify and respond to the needs and rights of persons with disabilities (Inter-Agency Standing Committee [IASC], 2019).

The development of new donor policies also encourages humanitarian actors to mainstream disability into their work. In 2019, the Directorate-General for European Civil Protection and Humanitarian Aid Operations (DG ECHO) released a **Guidance Note on the inclusion of persons with disabilities in EU-funded humanitarian aid operations** (DG ECHO, 2019). Such guidance focuses on mainstreaming disability at the programming level and includes a process indicator to measure the number of beneficiaries disaggregated by gender, age and disability.² In the same year, the **United Nations** adopted the **Disability Inclusion Strategy**, which contains an accountability framework with 15 performance indicators (United Nations, 2019). Other large humanitarian donors, notably the United Kingdom’s Department for International Development (DFID)³ and Australia’s Department of Foreign Affairs and Trade (DFAT), have published similar documents and demand clear deliverables for themselves and their partners to ensure that the humanitarian response efforts become more inclusive (see Department for International Development [DFID], 2018; Department of Foreign Affairs and Trade [DFAT], 2015). In addition, several key international frameworks and documents, such as the **Sendai Framework on Disaster Risk Reduction** (2015) and the **Global Compacts on Refugees and Migration** (2018) demand that signatories pay particular attention to the needs and specific requirements of persons with disabilities.

2 DG ECHO is currently reviewing some pilot indicators for measuring protection mainstreaming achievements, including disability inclusion (DG ECHO, 2019, p. 22).

3 The United Kingdom’s DFID was renamed the Foreign, Commonwealth and Development Office (FCDO) in September 2020. This report will refer to DFID as it was the name of the department during the research and writing phases.

However, evidence on how humanitarian actors strive to mainstream disability into their work and what factors support or undermine this process is still scarce.⁴ To strengthen humanitarian actors' disability-inclusion capacity, it is vital to have a more profound understanding of the conditions that impede and encourage the inclusion of persons with disabilities in the humanitarian response. This study therefore explores whether and how persons with disabilities are included in the operations of humanitarian actors in Cox's Bazar, Bangladesh, and whether these operations help improve the situation of persons with disabilities on the ground.

1.2 Local Background

The Rohingya refugee crisis is the main humanitarian challenge in the Asia-Pacific region (Mixed Migration Centre [MMC], 2019, p. 46). Following mass atrocities in the state of Rakhine in Myanmar in August 2017, an estimated 745,000 Rohingya fled to the Cox's Bazar district in Bangladesh (United Nations Office for the Coordination of Humanitarian Affairs [OCHA], 2019), where they joined existing Rohingya communities who had arrived in the region during previous waves of violence in 1978, 1992, 2012 and 2016. Some 870,000 Rohingya now reside in 34 extremely congested camps, located in the two *upazilas* (administrative areas) of Teknaf and Ukhiya (ISCG, 2020, p. 13). The situation in the camps is precarious and the vast majority of the refugees remain entirely dependent on humanitarian action (United Nations High Commissioner for Refugees [UNHCR] and REACH Initiative, 2019, p. 5). The Rohingya influx has also put an enormous burden on the host communities, which now compete for scarce resources with the refugees (ISCG, 2020, pp. 29–31).

In 2020, eight United Nations agencies and 117 international non-governmental organizations (INGOs) and national non-governmental organizations (NNGOs) provided protection, food, water, shelter, education, health care and other essential

⁴ For a broader perspective on vulnerability, see Funke and Dijkzeul (2021).

assistance to the Rohingya refugees,⁵ while simultaneously offering support to the affected Bangladeshi host communities.⁶ Thanks to their efforts, there have been improvements in the infrastructure and availability of services in and around the camps in the past two years, though camp conditions are still dire, with many refugees struggling to meet their daily needs (UNHCR and REACH Initiative, 2019; Reliefweb, 2019). Rohingya refugees also face serious protection and security risks, such as kidnapping, family separation, early marriage and childbearing and restrictions on freedom of movement.

Persons with disabilities are even more at risk of social exclusion than persons without disabilities because they face attitudinal, environmental and institutional barriers that prevent them from accessing crucial services and meaningfully participating in both the humanitarian response and daily life in the camps. These barriers include stigma and discrimination within the Rohingya communities, hilly terrain, a lack of space and inaccessible facilities and distribution points, the deliberate or unintentional exclusion of persons with disabilities in humanitarian activities, including income-generation programmes, and informal education.⁷

Most stakeholders interviewed for this study were aware of the multiple forms of discrimination and barriers that persons with disabilities experience on a daily basis and were actively working towards reducing the above-mentioned barriers. Several organizations entered into partnerships or formed consortia with international and national disability-focused organizations to strengthen their own capacities on including persons with disabilities in their programming.

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- 5** This report refers to the Rohingya people in Bangladesh as Rohingya refugees as they satisfy the criteria for refugee status under international law (see Wake and Bryant, 2018, p. 2). Myanmar refuses to use the term Rohingya. The Bangladeshi Government, which has not signed the 1951 Refugee Convention, and national organizations officially refer to the Rohingya in the country as ‘Forcibly Displaced Myanmar Nationals’.
- 6** Of these are 48 INGOs and 61 NNGOs (ISCG, 2020, p. 7).
- 7** Field notes, 15 and 28 January and 4 February 2020; interviews with humanitarian actors in Cox’s Bazar. The Bangladeshi Government restricts the right of the Rohingya to receive formal education.

Organizations are also increasingly reaching out to the Age and Disability Working Group (ADWG) to seek technical support on the inclusion of persons with disabilities in their response. Many humanitarian actors⁸ in Cox's Bazar have recently started changing their practices, though further sustained efforts are needed to mainstream disability into their programmes, organizational structures and the wider humanitarian response, in order to ensure the inclusion of persons with disabilities in humanitarian action.

1.3 Purpose and Key Research Questions

This report presents the findings from a four-week research stay in Cox's Bazar. It examines how humanitarian organizations mainstream disability into their response, along with the challenges they encounter. The aim of this report is to detect gaps and good practices in disability inclusion and to define entry points to close these persisting gaps and to replicate good practices. The study centres around three research questions:

1. How do humanitarian actors mainstream disability into the humanitarian response?
2. What factors challenge the inclusion of persons with disabilities in the Rohingya camps and host communities?
3. How can strategic partnerships and NGO consortia contribute to a more inclusive humanitarian response?

1.4 Relevance

This study makes an important contribution to identifying challenges and good practices in disability-inclusive humanitarian action and advancing shared understanding of necessary change processes in organizational structures and practice.

⁸ In this report, humanitarian actors comprise all actors providing humanitarian support to the Rohingya refugees and/or their host communities, regardless of whether they consider themselves as such.

The findings are not only relevant for humanitarian stakeholders in Cox's Bazar but may also inform disability-inclusive programming in other humanitarian contexts. The scholarly and societal relevance of this study can be summarized as follows:

- increase the understanding of conditions that impede and encourage the inclusion of persons with disabilities in the humanitarian response
- identify challenges and good practices on disability-inclusive humanitarian action
- inform humanitarian responses with regard to the inclusion of persons with disabilities.

1.5 Report Structure

This report is divided into five chapters. Chapter 1 introduces the report and chapter 2 details the data collection and analysis methods used. Those who are primarily interested in the situation in Cox's Bazar may skip directly to chapter 3, which provides a contextual overview of the situation in the camps and host communities and outlines the barriers and multiple forms of discrimination that persons with disabilities face and experience. Chapter 4 examines disability mainstreaming in humanitarian action. It first describes three forms of collaboration (donor-recipient partnerships, NGO consortia and the ADWG), before outlining the challenges that impede the inclusion of persons with disabilities in humanitarian action. Chapter 5 summarizes the findings, provides potential areas for further research and makes recommendations on how to improve disability-inclusive humanitarian action.



2. Methodology

This report takes an explorative and qualitative approach due to the limited availability of ethnographic and impact studies on how humanitarian actors mainstream disability into their work and lack of large-scale studies on staff and organizational behaviour. The use of a qualitative research strategy allows for a nuanced understanding of practices and local dynamics that either encourage or limit the inclusion of persons with disabilities in humanitarian programmes, organizational structures and the wider humanitarian coordination system.

2.1 Case Selection

Cox's Bazar was selected as a case study to explore disability inclusion in the Rohingya humanitarian response for five reasons. First, the research could focus on disability-mainstreaming activities in a large-scale refugee crisis where hundreds of stakeholders are involved in the humanitarian response. The crisis is now moving into its third year and is becoming increasingly protracted. The conditions are not favourable for repatriation and the refugees and their host communities are likely to depend on humanitarian action in the years to come. The findings of this study can therefore inform ongoing and future humanitarian activities in Cox's Bazar.

Second, many humanitarian organizations are aware of the numerous barriers that persons with disabilities experience and have started changing their practices to mainstream disability into their work.

Third, the ADWG strives to promote the inclusion of persons with disabilities in the wider humanitarian response. This makes Cox's Bazar an excellent context to study disability inclusion within individual organizations and the larger humanitarian coordination structure.

Fourth, HI, Christian Blind Mission (CBM) and Centre for Disability in Development (CDD) maintain a strong presence on the ground, which widened the scope of the research significantly.

All three organizations have been involved in supporting inclusive humanitarian action by providing technical support and capacity-building to different partner organizations, including United Nations agencies and INGOs and NNGOs. Each organization also helped facilitate contact with interviewees, camp visits, participation in meetings and the review of various internal documents on their activities related to disability-inclusive humanitarian action.⁹

Finally, the environment was sufficiently safe and stable for a research stay. This allowed the researcher to speak with representatives of a large number of organizations at a location of the representatives' choice, visit organizations' projects in the refugee camps and host communities, and attend a number of meetings with key stakeholders involved in the humanitarian response.

Importantly, the humanitarian sector in Cox's Bazar has initiated a process to become more disability-inclusive. This process to inclusion, which involves adjusting systems, changing mindsets and building capacities, takes time and poses many challenges (as highlighted in this report), all of which the sector is now working to overcome.

2.2 Data-collection Methods

Research in Cox's Bazar was carried out for four weeks in January and February 2020. It involved: key informant interviews with 32 individuals from 18 organizations; one focus group discussion with eight field staff from an international mainstream humanitarian NGO working in protection in the refugee camps and host communities in Teknaf and Ukhiya; and participant observations in three HI team meetings, one meeting of the Protection Cluster Working Group led by the United Nations High Commissioner for Refugees (UNHCR), and one meeting of the ADWG.

9 CBM and CDD jointly implement all of their projects to benefit from each other's experience and expertise. The organizations refer to this collaboration as a 'partnership approach'. Since the ADWG does not implement any projects, the two organizations are mentioned separately in activities that refer to the ADWG.

It also included field visits to Camp 17 and Kutupalong RC¹⁰ with HI staff, along with visits to Camps 13, 15 and 19 and to the host community in Ukhiya with the CDD (see Maps 1 and 2). Two Skype interviews with a representative from a disability-focused organization and one local government entity were conducted in October 2020 and January 2021 respectively to gain insights about the latest developments in the humanitarian response with respect to disability inclusion.

Thirty expert interviews were conducted in person in Cox's Bazar and four expert interviews over Skype. HI and CBM staff contacted their project partners in advance of the research stay. The response rate for the interviews was very high, with some interviews arranged spontaneously by the researcher. All except one interviewee gave permission to record and transcribe their interviews. To ensure confidentiality, the names and affiliations of the interviewees and informants are kept anonymous in this report.

Interviewees were first asked general questions about the mission of their respective organization, the length of their presence in Bangladesh and Cox's Bazar in particular and their fields of operation since the start of the Rohingya crisis in August 2017. Following this, questions focused on the measures or actions that organizations have taken to include persons with disabilities into their programmes and organizational structures. Of particular interest was how these organizations (attempt to) promote the participation of persons with disabilities, remove existing barriers, empower persons with disabilities and disaggregate data on age, gender and disability to monitor inclusion. Other questions explored the work within consortia and other formalized partnerships and the role of donors in supporting disability-inclusive programming. These questions aimed to uncover factors that enable or undermine disability mainstreaming, as well as ways to strengthen existing efforts to mainstream disability.

10 Kutupalong is a refugee camp in Ukhiya. The abbreviation 'RC' (registered camp) refers to a section within the camp that was established before the mass influx of Rohingya Muslims into Cox's Bazar in 2017. It is one of two government-run refugee camps in Cox's Bazar, the other being Nayapara, which is located south of Kutupalong. Together, they host approximately 45,500 refugees (UNHCR, 2019a).

The study also included a review of internal HI and CBM documents (reports, internal evaluations, project proposals), which covered current and previous projects on disability-inclusive humanitarian action in Cox's Bazar.

2.3 Data-analysis Methods

Data was analysed using MAXQDA. Semantic categories were deductively derived from international tools that promote the inclusion of persons with disabilities in humanitarian action and from the interview guide. These categories include 'data collection', 'participation' and 'empowerment'. In this way, the analysis could detect practices that organizations undertake to mainstream disability. One category centred on 'collaboration and cooperation' between different actors in Cox's Bazar and included several subcategories on partnerships between mainstream and disability-focused organizations, consortia and working groups.

Several interview partners highlighted challenges in their daily work and their impact on mainstreaming activities. This category of 'challenges' included several subcategories, such as 'high staff turnover', 'work in silos' and 'short funding cycles'. Another category focused on the barriers that persons with disabilities experience, divided into 'attitudinal', 'environmental' and 'institutional' barriers. Many respondents commented on these barriers, and as mentioned previously, demonstrated a high level of awareness of the multiple forms of discrimination that persons with disabilities face in the camps and host communities. The main challenge, however, still concerns how to remove these barriers.

2.4 Limitations

This study has three important limitations. First, it does not evaluate specific projects and the degree to which they include persons with disabilities. To give interview partners the opportunity to speak openly about the challenges and opportunities they encounter in their daily work with respect to disability-inclusive humanitarian action, the identity and affiliation of interviewees were anonymized. This report cannot therefore give precise descriptions of the internal dynamics within individual projects, partnerships and consortia projects.

Second, the study mainly includes interviews with representatives of international and national organizations that collaborate with HI, CBM or CDD to enhance their capacities on disability-inclusive humanitarian action. One interviewee was employed at an NGO that did not have a formal partnership with HI, CBM or CDD. The study cannot assess the extent to which organizations without a formal partnership with disability-focused organizations include persons with disabilities in their humanitarian programming.

Third, due to access conditions, the researcher was only permitted to visit the camps and could not interview or hold focus groups with the refugees to understand their perspectives on the humanitarian community's efforts to mainstream disability (though the researcher was able to speak with a group of beneficiaries with disabilities in the host communities). As a result, the contextual overview on inclusion barriers relies on reports, observations and expert interviews with humanitarian staff.

A comprehensive, systematic evaluation of relevant guidelines and standards and how they inform humanitarian practice in various contexts is needed but requires more in-depth and comparative research that is beyond the scope of this study.



3. Contextual Overview: Persons with Disabilities in the Camps and Host Communities

Persons with disabilities constitute approximately 15 per cent of any population (World Health Organization [WHO] and World Bank, 2011, p. 27). As stated, they are among the most marginalized in crisis-affected communities (United Nations General Assembly [UNGA], 2016) and face attitudinal, environmental and institutional barriers that put them more at risk of exclusion than others. These barriers prevent them from safely and equally participating in humanitarian programmes and accessing crucial services. This is no different in Cox's Bazar, where persons with disabilities face serious challenges in participating in programmes and accessing distribution points, safe spaces and service and sanitation facilities (see Aktion Deutschland Hilft, Centre for Disability in Development [CDD] and Arbeiter-Samariter-Bund [ASB], 2017; HelpAge International, 2019; HI, 2019). The education sector, for example, estimates that due to the lack of ramps, the steep, rough terrain and the unavailability of inclusive learning materials, "children with disabilities [in the camps] are 10 to 40 percent less likely to attend learning facilities than children without" (ISCG, 2020, p. 70).

This chapter provides an overview of the barriers persons with disabilities face, focusing on the situations in the camps and host communities.¹¹ To understand what factors enable or impede the inclusion of persons with disabilities and how humanitarian actors can enhance their disability-mainstreaming capacities, it is vital to have a general understanding of the context in which they operate.

¹¹ This overview cannot replace a comprehensive needs assessment and does not claim to be all-inclusive.

3.1 Situation in the Camps

In January 2021, there were 870,000 Rohingya refugees in the Cox's Bazar district (Government of Bangladesh and UNHCR, 2019). This number is slightly lower than previous estimates¹² and based on a joint verification exercise between the Government of Bangladesh and UNHCR that was started in 2018 and continued throughout 2019. More than 590,000 refugees reside in the Kutupalong-Balukhali Expansion Site that lies 35 kilometres (22 miles) outside the town of Cox's Bazar, where most organizations and the Office of the Refugee Relief and Repatriation Commissioner (RRRC) are located. The size of the camp area increased rapidly from 0.4 km² in January 2016 to 9.5 km² in February 2018 and to almost 15 km² in December 2018 (Benz, et al., 2019; ISCG, 2019, p. 12). Combined with the camp areas south of the Kutupalong-Balukhali Expansion Site, the Government of Bangladesh has allocated a total of 26.3 km² of land (6,500 acres) to the Rohingya refugees (ISCG, 2019, p. 12). Before the Rohingya influx, most of the land was covered by forests, where the lack of infrastructure, especially during the early stages of the response, made service provision extremely difficult (Ibid., p. 37). In 2018 and 2019, significant construction was carried out in the area, leading to the development of a solid drainage system and a network of auxiliary roads, the latter of which was expanded in 2020 with support from the Asian Development Bank and the World Bank (ISCG, 2020, p. 20). However, the heavy deforestation and its adverse impacts on the climate have exacerbated the risk of landslides and flooding during the monsoon and cyclone seasons. Furthermore, the proximity of shelters poses serious risks, such as fire hazards and the spread of communicable diseases (ISCG, 2019, p. 37). With the outbreak of the COVID-19 pandemic in Cox's Bazar, the authorities imposed a partial lockdown of the district and only allowed humanitarian actors to deliver critical services to the refugees (Reliefweb, 2020, p. 2; RFI, 2020). Meanwhile, several INGOs noted that the security situation in the camps is gradually deteriorating, with the outbreak of internal clashes between Rohingya groups, which has forced "hundreds of families to flee their shelters" since September 2020 (Reliefweb, 2020, p. 3). Most of these refugees have found shelter with their (extended) family members in other camps.

12 Previous estimates indicated that more than 900,000 refugees would reside in the camps in Cox's Bazar district (ISCG, 2019, p. 10).

3.2 Refugees with Disabilities: Perceptions and Barriers

According to the ISCG (2019, p. 10), the Government of Bangladesh considers the crisis as a short-term challenge and refers to the Rohingya as 'Forcibly Displaced Myanmar Nationals', rather than refugees.¹³ In this context, human rights advocates and numerous INGOs have raised strong concerns about the obstacles that Rohingya refugees experience in exercising their fundamental rights and freedoms, including their right to education, livelihoods and full integration into the host communities (see Human Rights Watch, 2019; Amnesty International, 2020; Reliefweb, 2020).¹⁴ In January 2020, the Government began to allow education and formal schooling for 10,000 Rohingya pupils under a new pilot programme led by the United Nations Children's Programme (UNICEF) (2020), while some refugees found work as day labourers or volunteers in small cash-for-work projects financed by the humanitarian actors (Wake and Bryant, 2018, p. 8). However, the official focus on repatriation constrains refugees' capacity to pursue a lasting solution and build a life in their places of refuge. In response, the United Nations Special Adviser on the Prevention of Genocide underlines that "it is imperative [...] that the Rohingya, while in Bangladesh, are afforded more chances to uplift themselves educationally and through access to livelihoods" (United Nations, 2018).

For refugees with disabilities, the situation in the camps is even more difficult than for those without disabilities. As mentioned previously, persons with disabilities face numerous barriers that prevent them from accessing crucial services and meaningfully participating in the humanitarian response. Most evident are the environmental barriers that hinder them from accessing registration and distribution points and WASH facilities, including latrines, bathing units and spaces for menstrual hygiene management, as well as various service facilities and so-called 'safe spaces' for children and women. These facilities are either located far away, uphill and across difficult terrain or are constructed in such a way that they are difficult for persons with disabilities to access or operate.

¹³ See also footnote 4.

¹⁴ Twenty-seven organizations signed the statement, including, CARE, Danish Refugee Council (DRC), HI, Norwegian Refugee Council (NRC) and World Vision.

Buildings and shelters tend to have steps and narrow entrances, and latrine blocks are too narrow to accommodate a support person and persons using a wheelchair or mobility aids. During monsoon and cyclone seasons, service facilities are even harder to access because roads and bridges are flooded or become very slippery. Regrettably, these barriers are extremely difficult to address once they are established. The overcrowding of the camps limits the available space for an expansion or remodelling of existing facilities. As one respondent explained:

Some service facilities are not in a good location. Some of them are very close to busy roads. [...] But again, I understand, the acquisition of land is a bit of a problem, so to get appropriate land where services are safe and easy to access could be a challenge.

Interview 14, representative of an INGO.

Moreover, stigma, discrimination and negative attitudes towards persons with disabilities within the communities mean that persons with disabilities rarely leave their makeshift shelters and become 'invisible' in the camps. If they do leave their shelter and have a visible impairment, they face increased stigma.

I've seen people being carried in a basket, but I don't know what can be done, whether there's a solution for that. It really distracts me whenever I see it because it picks up a lot of attention and people just stand and stare and talk about it – I don't see it as dignifying.

Interview 8, representative of an INGO.

Rohingya refugees also display extremely negative attitudes and scepticism towards health services due to an overloaded health-care system in the camps, lack of confidence in alternative health-care services, lack of communication and

accountability between health workers and patients and previous experiences in Myanmar, which often required the Rohingya to seek alternative practices from traditional healers, herbalists or faith and religious healers (ACAPS, 2020, p. 4). As a result, Rohingya refugees are hesitant to accept psychosocial support, physiotherapy and other types of rehabilitation services from disability-focused organizations. For example, instead of doing regular exercises to support recovery, Rohingya refugees tend to prefer injections as a cure.¹⁵

Interviewed humanitarian workers did not express negative attitudes or prejudices towards persons with disabilities during the research. However, there are persisting misconceptions within the humanitarian community, which lead to wrong assumptions on the needs, capacities of, and barriers faced by persons with disabilities in the camps, including how to identify and address them. One interviewee admitted:

We always think about those who use a wheelchair and most of the time the response is: ‘Let’s build a ramp!’ But a ramp will not be helpful for people with different types of disabilities.

Interview 22, representative of an INGO.

Promoting meaningful participation and involvement of persons with disabilities in needs assessments and the planning, implementation and monitoring of humanitarian programmes would help eliminate these misconceptions (IASC, 2019, p. 19) and promote an inclusive response. So far, however, refugees in the camps rarely participate in decisions affecting their lives (Wake and Bryant, 2018, p. 7). Although humanitarian organizations are increasingly engaging refugees in consultation meetings and focus group discussions, persons with disabilities are regularly excluded (ISCG, 2020).¹⁶

¹⁵ Field notes, 24 January and 4 February 2020.

¹⁶ Interview 22. See also Human Rights Watch (2020a); Human Rights Watch (2020b); Reliefweb (2020).

Moreover, complaint and feedback mechanisms – even those of disability-focused NGOs – are often not accessible or available in multiple formats.¹⁷ Some organizations try to address these gaps, yet respondents emphasized that they need to be more deliberate in reaching out to persons with disabilities. One respondent said:

We established a women's participation committee of 100 members, but we realized that women with disabilities were not included. So we added ten more member spots so that they could then be invited. Now we have 110 members, including ten women with disabilities.

Interview 5, representative of a United Nations agency.

Overall, the participation of persons with disabilities depends too much on the efforts of individual organizations and staff members. To change this, it is crucial to identify persons with disabilities, along with their needs, capacities and the barriers they face within programmes and the wider humanitarian response. In Cox's Bazar, systematically disaggregated data on gender, age and disability do not exist and only a few organizations have started incorporating the Washington Group question sets into their surveys and assessments.

Box 1. Tasmin: Targeted Assistance to Persons with Disabilities to Foster their Inclusion in the Camps

Tasmin* is an 18-year-old woman who lives with her family of ten in a makeshift shelter in Camp 17. She has Guillain-Barré syndrome, a rare disorder in which the immune system attacks healthy nerves.

¹⁷ Field notes from 24 January 2020.

The syndrome paralysed her whole body and she was unable to leave the shelter for months, making her entirely dependent on her family's support. She is now slowly recovering and thanks to rehabilitation services organized by Humanity & Inclusion (HI), her muscles are strengthening, which is helping to restore some movement. It is likely she will fully recover. Until then, treatment and support to the family by HI's mobile team will continue, if funding allows.

* Name has been changed.

Box 2. Washington Group Questions

The Washington Group on Disability Statistics has developed tools to measure disability in line with the functional approach of the International Classification of Functioning, Disability, and Health of the World Health Organization (WHO). They avoid the term 'disability' and instead only address limitations in undertaking basic activities. Originally designed for large-scale national questionnaires, development and humanitarian organizations increasingly use them for their own purposes. Most often, they apply the Washington Group Short Set (WG-SS) of questions, which covers six core domains: walking, seeing, hearing, cognition, self-care and communication. Each question has four response categories: 1) No, no difficulty; 2) Yes, some difficulty; 3) Yes, a lot of difficulty; 4) Cannot do it at all (Cheshire and Humanity & Inclusion [HI], 2018, p. 7). The Washington Group also has additional tools for situations that require more detail or concern children.

Note: The Washington Group on Disability Statistics was founded in 2001 to develop standard indicators of disability in surveys and censuses by national statistics offices. It was established under the United Nations Statistics Commission. For more information on the Washington Group, see [their website](#).

3.3 Situation in the Host Communities

The Cox's Bazar district, with a total Bangladeshi population of 2,650,000, is one of the country's poorest districts (ISCG, 2020, p. 29). Poverty levels are well above the national average and there are reports that many locals survive on just one meal a day.¹⁸ The Rohingya influx directly impacted the food security of the local population, as many lost access to farming land and forests. Many locals now compete with the refugees for work opportunities, with their arrival having driven down day-labour wages in Teknaf and Ukhiya by 11 percent and 17 percent, respectively (Ibid., p. 31). The refugee crisis has also negatively impacted the environment due to considerable deforestation and host communities are concerned about the perceived deterioration of security. Drug trafficking from Myanmar through Teknaf, Cox's Bazar and the region's markets has been increasing in recent years, and human trafficking both inside and outside the camp areas remains an ongoing issue (Ibid.; field notes from 13 January 2020). Road congestion and the deterioration of public services have also further strained the relationship between locals and the refugees (ISCG, 2020, p. 30).

According to ISCG, the host communities do not believe that they have benefitted from the humanitarian response and criticize the humanitarian community for overlooking their most urgent needs (Ibid., p. 58). However, some respondents argued that these complaints were not always justified, when, for example, they came from locals with good jobs, sufficient food to feed their family and houses with decent sanitation facilities.¹⁹ Some Bangladeshi locals have benefitted from the refugee response, for example, through employment in humanitarian organizations or local businesses, which have profited from the large United Nations and NGO presence in the district (Wake and Bryant, 2018, p. 9). Moreover, the Government requires 30 per cent of all humanitarian funding to be spent on the host community. Overall, measuring the concrete impact of the United Nations and NGO presence on the local economy is difficult and enhanced assistance and services for particularly vulnerable and marginalized groups in the host communities are needed to mitigate protection risks and inter-community tensions (ISCG, 2020, p. 58).

¹⁸ Field notes, 4 February 2020.

¹⁹ Field notes, 24 January 2020; conversation with NNGO staff.

3.4 Persons with Disabilities in the Host Communities: Perceptions and Barriers

Officially, Bangladesh attaches great importance to the inclusion of persons with disabilities in society. It was one of the first countries to sign the CRPD and its Optional Protocol, and in 2013 passed a national policy – the Rights and Protection of Persons with Disabilities Act. This act approaches disability from a human rights perspective and promotes inclusive education, accessibility in all public places, equal opportunities in employment and the protection of inherited property rights. A number of accountability mechanisms at different administrative levels oversee the implementation of the act and strive to protect the rights of persons with disabilities. Nevertheless, persons with disabilities still face many barriers that prevent them from fully enjoying their human rights. As in many developing economies, roads and infrastructure in the district are in poor condition and public buildings and local transport are not accessible for persons with limited mobility because the authorities lack the financial means to remodel the infrastructure at a faster pace. The availability of data is poor due to the lack of officially published national statistics on persons with disabilities and limited comprehensive needs assessments of host populations carried out by humanitarian actors.²⁰ Moreover, respondents reported that employees of local government institutions are working to become more inclusive, but often lack awareness about the specific rights of persons with disabilities and international and national protection standards.²¹ In host communities, persons with disabilities also face stigma and discrimination and many people still perceive them as ‘passive victims’, who lack any sense of agency.

20 A Household Income and Expenditure Survey (HIES) from 2010 found that 9 per cent of all citizens have a disability, while a World Bank case study on disabilities in Bangladesh estimated that 16.2 per cent of all working age people in Bangladesh had some kind of disability (Swedish International Development Cooperation Agency [Sida], 2014, p. 1). In the 2016 HIES estimate, the number was lower at 6.94 per cent. See Ministry of Planning, Statistics and Informatics Division and Bangladesh Bureau of Statistics (2016).

21 Some international organizations and scholars also raise the issue of corruption (see Risk and Compliance Portal 2020 and BdNews 2019).

One respondent explained:

In Cox's Bazar, persons with disabilities face a lot of discrimination. I have bitter experiences here. The communities don't think that persons with disabilities can organize, do advocacy work or raise their voices.

Interview 24.

Box 3. Nadim: Inclusion in the Host Community

Nadim* is a 62-year-old man who lives with his family and some cattle on a small hill near the refugee camps. Nadim owns a shop, where he sells food items. After a stroke in 2019, which left him paralysed, he was unable to run his small business. The Centre for Disability in Development's (CDD) mobile team of physiotherapists gave him weekly treatment and made temporary adjustments to his house, which have enabled him to leave his property and walk down the hill. Soon he will be able to start running his business again.

* Name has been changed.

The absence of OPDs in most parts of Cox's Bazar is likely to contribute to this perception. Although Bangladesh has an active civil society with around 300 organizations working on the promotion of disability rights (Sida, 2014), there are just 12 OPDs in Cox's Bazar. These OPDs operate from the two *upazilas* of Sadar and Ramu, and not in Ukhiya and Teknaf, where the refugees are currently living.²² As such, persons with disabilities who live in communities adjacent to camps have not had the opportunity to make their views and opinions heard in the humanitarian response. Disability-focused organizations have started engaging representatives

22 Interview 24.

from OPDs in other parts of Bangladesh as consultants to give a voice to persons with disabilities. Moreover, to ensure the active participation and empowerment of persons with disabilities, organizations have encouraged the establishment of peer-support and community network groups in Ukhiya and Teknaf (information from internal documents of disability-specific NGOs). Some progress has been made in Ukhiya, where local authorities have started to collect data on disability, set up an information help centre and closely cooperate with disability-focused NGOs to make education more inclusive.²³

3.5 Conclusion

In summary, persons with disabilities in Cox's Bazar face many barriers and multiple forms of discrimination that hinder their safe and equal access to and meaningful participation in the humanitarian response. It is worth highlighting that persons with disabilities are not a homogeneous group; their needs differ depending on the intersection of various factors, including age, gender, health status, type of impairment and the individual support they receive from caregivers and community members, among other factors. Data disaggregated by age, gender and disability, along with comprehensive needs assessments are therefore crucial for an effective humanitarian response but have not been sufficiently collected. Fortunately, the humanitarian community and the Government of Bangladesh are building on past experiences and increasingly including persons with disabilities and other at-risk groups in their response, and are also working towards closing existing gaps, though much work remains to be done.

The challenges and opportunities to achieve this differ across the camps and host communities. Although the material circumstance of particularly vulnerable segments of the host population, including persons with disabilities, may be similar to those of the Rohingya refugees, the situation in the host communities is fundamentally different. As Bangladeshi citizens, vulnerable populations have rights and freedoms to which the Rohingya, as foreigners, have no access. These include, for example, the right to education, freedom of movement and the ability to establish self-help groups and OPDs, which if available, would enhance the ability of the Rohingya to create a more enabling environment for claiming and enjoying their rights (Amnesty International, 2020; Reliefweb, 2020).

²³ Skype interview with a local government official, January 2021.



4. Disability Inclusion in Humanitarian Action: Partnerships and Consortia

To fully include persons with disabilities in humanitarian action, it is often necessary to provide targeted measures and integrate disability-sensitive measures into the design, implementation, monitoring and evaluation of all projects and programmes (the so-called ‘twin-track’ approach). The latter is commonly referred to as ‘disability mainstreaming’ (IASC, 2019, p. 19), a term which has no universal definition. The IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action describe it as "the process of incorporating CRPD in protection principles, promoting the safety and dignity of persons with disabilities, and ensuring they have meaningful access to humanitarian support and can participate fully in humanitarian interventions" (Ibid., p. 10). In combination with targeted measures, mainstreaming is therefore a strategy to safeguard the rights of persons with disabilities during humanitarian emergencies and achieving their inclusion in humanitarian action. The inclusion of persons with disabilities is most successful when humanitarian actors observe four ‘must do actions’ that apply in each sector and in all phases of the humanitarian response (Ibid., pp. 19–21):

1. promote meaningful participation of persons with disabilities
2. remove barriers
3. empower persons with disabilities, support them to develop their capacities
4. disaggregate data for monitoring inclusion.²⁴

24 These points are similar to and reflect the three key areas of inclusion in the Humanitarian Inclusion Standards (ADCAP, 2018, p. 10): 1) data and information management; 2) addressing barriers; 3) participation of older people and people with disabilities, and strengthening of their capacities.

As stated, almost all key stakeholders overlooked persons with disabilities in the early phase of the humanitarian response, failing to promote their meaningful participation and identify their needs, capacities and the barriers they face. As a result, persons with disabilities have been left behind, further increasing their exclusion, marginalization and protection risks. However, following the end of the acute emergency phase in 2018, some organizations began to recognize that their responses were not inclusive. One interview partner noted:

You can see now, and especially within the Protection Working Group and task team, that persons with disabilities are becoming a greater concern and are increasingly included in the agenda of the humanitarian organizations.

Interview 28, representative of an INGO.

When asked about the motives for this change, respondents cited two main reasons. First, that donors are increasingly demanding clear deliverables on the inclusion of persons with disabilities in humanitarian programmes. Second, that members of the Rohingya and host communities frequently raise issues on disability inclusion in consultation meetings and key informant interviews with humanitarian field staff.

The strategies for mainstreaming disability and strengthening organizational capacities in this regard slightly differ among organizations. However, all measures focus on changing data-collection methods, removing existing barriers and increasing the participation of persons with disabilities in consultation meetings, focus group discussions and activities.²⁵ To achieve tangible results, all organizations in this study relied on HI, CBM and CDD for technical support, with

25 This is in line with the four 'must do actions' of the IASC Guidelines and the three key areas of inclusion of the Humanitarian Inclusion Standards. However, the empowerment of persons with disabilities is more difficult to achieve because as mentioned previously, refugees are not permitted to establish OPDs and there are none from the host communities where the camps are located. This issue will be discussed in the next sections.

some receiving additional technical input from disability inclusion experts within their own organizations both at the headquarters level and in Cox's Bazar. A few mainstream NGOs employed managers who had previously worked for disability-focused organizations and already had a sound understanding of disability and inclusion. Yet, all respondents believed that the collaboration with disability expert organizations such as HI, CBM or CDD was crucial for advancing disability mainstreaming in their programmes and organizational structures as well as the wider humanitarian response. It is therefore unsurprising that the demand for technical expertise from HI, CBM and CDD in Cox's Bazar was high. However, due to a lack of sufficient resources, the organizations were not able to respond to all requests. One respondent noted:

There is so much demand. There is a momentum. We have to streamline our work because there are so many demands coming in now.

Interview with staff from a disability-focused NGO.

To meet some of these demands, HI, CBM and CDD independently formed partnerships with United Nations agencies and mainstream NGOs. Importantly, they also established the ADWG in collaboration with HelpAge International to promote inclusive humanitarian action in the wider humanitarian response. Overall, three types of collaboration to foster the inclusion of persons with disabilities were identified: 1) donor-recipient partnerships; 2) NGO consortia; and 3) the ADWG. The following sections will briefly describe the working modalities of these partnerships.

4.1 Donor-recipient Partnerships: United Nations Agencies and Disability-focused Non-governmental Organizations

Donor-recipient partnerships are those formed between United Nations agencies and disability-focused NGOs. Under such a partnership, organizations such as HI, CBM or CDD receive funding to provide targeted assistance to persons with disabilities in the camps and/or host communities, while simultaneously

strengthening the capacities of the donor organization and its implementing partners through capacity-building and technical support.²⁶ In most cases, the organizations agree on joint indicators and work plans, which facilitate collaborative efforts and accountability. Often these partnerships are of a strategic nature and entail a financial commitment of the donor to support the work of the disability-focused NGOs. In this case, the disability-focused NGO receives funding to procure and distribute assistive devices to persons with disabilities and to provide rehabilitation services. United Nations agencies and disability-focused NGOs sometimes also maintain some loose form of collaboration by which the disability-focused NGO provides capacity-building or technical support on an ad hoc basis, but without allocated project funding (**a collaboration without allocated funding**). These collaborations may follow up on previous partnerships or may lead to donor-recipient partnerships at a later time.

4.2 Non-governmental Organization Consortia

NGO consortia are becoming increasingly popular in humanitarian action. Consortia are a special form of collaboration between organizations with the same donor. These organizations come together as partners, operate within a single financial and reporting framework and develop common objectives (Krishnan, 2017, p. 459). The number and composition of the members, the modes of cooperation and the management structures of consortia can vary significantly, even within a single humanitarian context.

The general idea behind the formation of consortia is to reduce duplication of humanitarian services, increase the geographic coverage of interventions and share and complement existing expertise among its members (Macharia, 2016, p. 3). However, the effectiveness of consortia on the delivery of humanitarian action is under-researched. Evidence suggests that they are most successful when partners define common objectives, ensure effective leadership, develop an understanding of capacities, structures and systems within different organizations, demonstrate reliable commitment to their objectives, systematically allocate time

26 Disability-focused organizations are also open to other forms of cooperation, for example, with INGOs, NNGOs or local disability-focused NGOs, as well as forms of partnership that include capacity-building measures (and not targeted services).

to consortium activities, ensure transparent and effective communication, clarify roles and responsibilities, agree on member contributions for external funding, find common approaches to reporting and monitoring, and allow members to change or end activities that are not working (Emergency Capacity Building Project, 2012).

In Cox's Bazar, disability-focused organizations joined consortia with INGOs and NNGOs to strengthen their capacity on inclusive humanitarian action. Within these projects, the disability-focused organizations provided technical support and capacity-building to other consortia members, which operate in various sectors (for example, health, nutrition, WASH, education, protection) and across different camp areas. While the role of disability-focused organizations varies within partnerships and types of consortia, it typically includes implementing a range of activities, such as: awareness-raising and training sessions on disability inclusion and inclusive humanitarian action; technical support and capacity-building on inclusive programming; and monitoring, evaluation and learning, with a focus on the collection, analysis and use of disaggregated data on persons with disabilities and on the identification of barriers and enablers to inform inclusive programming.

4.3 Age and Disability Working Group

HI, CBM, CDD and HelpAge International established the ADWG to promote an inclusive humanitarian response towards persons with disabilities and older persons within the refugee camps and host communities. Recently, CBM and CDD contracted an OPD consultant to participate in the ADWG.²⁷ It is intended that member organizations chair the ADWG on a rotational basis. As of late 2019, the ADWG has employed a dedicated coordinator that facilitates communication and coordination among its members and serves as a focal point to other humanitarian organizations in Cox's Bazar.

²⁷ As indicated, a clear hindrance for the participation of persons with disabilities during the early stages of the response was the absence of OPDs in Cox's Bazar. Apart from the founding organizations, the Disabled Persons' Organization (DPO)-Cox, International Committee of the Red Cross (ICRC), Resource Integration Centre (RIC), Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV), Young Power in Social Action (YPSA) and Centre for the Rehabilitation of the Paralysed (CRP) are members of the ADWG. Other organizations regularly attend their meetings.

The ADWG operates under the Protection Working Group. In February 2020, it agreed on a coordination framework, which grants the ADWG observer status in the Protection Working Group's task team.²⁸ Among the ADWG's responsibilities is to support the protection sector through identifying protection and programmatic concerns, contribute to age and disability response strategies, strengthen coordination with relevant authorities on age- and disability-related issues, and support information management and data collection. Through strategic engagement with other sectors, including health, WASH and education, the ADWG also seeks to ensure that age and disability mainstreaming occurs throughout the whole response.²⁹

4.4 Partnerships, Consortia and the Age and Disability Working Group: Approaches to Disability Inclusion

These three forms of cooperation have the potential to contribute to a more inclusive humanitarian response. The donor-recipient partnerships, NGO consortia and ADWG are excellent starting points to raise awareness on the rights of persons with disabilities and enhance the capacities of mainstream actors in collecting and analysing disaggregated data, reducing existing barriers and enhancing the participation of persons with disabilities in humanitarian activities, mainly because they allow disability-focused NGOs to work with a specific set of partners in a structured, collaborative manner.³⁰ Each partnership or cooperation presents a unique set of opportunities and challenges for the inclusion of persons with disabilities. The following sections will discuss these in detail.

4.4.1 United Nations Agencies and Donor-recipient Partnerships

As of February 2020, there were six United Nations agencies involved in the Rohingya response at the camp level, namely the International Organization for Migration (IOM), UNHCR, the World Food Programme (WFP), UNICEF, the

28 This is a technical expert group on policy issues. It includes: UNHCR, HI, DRC, Oxfam, BRAC, NRC, ActionAid, UNICEF, World Vision and the International Organization for Migration (IOM).

29 For an overview of the objectives, see Protection Working Group (2020).

30 As mentioned previously, the empowerment of persons with disabilities in the camps and host communities is more difficult to achieve.

United Nations Population Fund (UNFPA) and the United Nations Entity for the Empowerment of Women (UN-Women) (OCHA, 2020). In addition, the United Nations Development Programme (UNDP) and the World Bank supported the Cox's Bazar District Administration with coordinating humanitarian and development projects in the host communities (ISCG, 2020, p. 29). All United Nations agencies rely on INGOs and NNGOs to carry out activities at the field level. The number of implementing partners varies per organization and sector, but large organizations "will have about six to ten partners" per sector in which they operate.³¹

The United Nations assumes a leading role in promoting the inclusion of persons with disabilities, and as mentioned, adopted a Disability Inclusion Strategy in 2019 "to strengthen system-wide accessibility for persons with disabilities and the mainstreaming of their rights" (United Nations, 2019). The strategy builds on previous disability-mainstreaming tools that individual United Nations agencies have published over the course of the last decade (see UNICEF, 2017; United Nations Relief and Works Agency for Palestine Refugees in the Near East [UNRWA], 2017; UNDP, 2018; UNHCR, 2019b). Against this background, it is not surprising that the United Nations agencies in Cox's Bazar demonstrate a firm commitment to the inclusion of persons with disabilities, for example, by hiring disability inclusion experts to support their work. Yet not every United Nations agency has a donor-recipient partnership with a disability-focused NGO, and some are more advanced than others in terms of collecting disaggregated data, removing barriers and promoting the participation of persons with disabilities. In fact, many United Nations agencies have just started to change their processes and are still struggling to include persons with disabilities in their humanitarian operations.

Interviews with United Nations staff suggest that organizations that had substantial support from their headquarters were more advanced in promoting the inclusion of persons with disabilities and were more likely reach out to disability-focused NGOs for enhanced collaboration and capacity-building. These organizations often benefitted from the support of their own inclusion experts and relied on dedicated financial resources to make necessary changes at the strategic and operational levels.

³¹ Interview 5, representative of a United Nations agency.

However, it is not possible to determine whether some United Nations agencies are more disability-inclusive than others. Respondents highlighted that the level of commitment varied across different missions worldwide.

From my discussions with the community, I think that some missions have done a better job than others [in including persons with disabilities]. For example, the South Sudan, Iraq and Bangladesh missions have been a bit more proactive.

Interview with a United Nations staff member.

In Cox's Bazar, one United Nations agency is particularly active in pushing for changes within their humanitarian operations. It engages in large-scale staff training, has developed a draft action plan on disability inclusion for two organizational sectors, maintains partnerships with disability-focused NGOs, regularly participates in ADWG meetings and creates advocacy material to document good practices on disability inclusion. Most recently, one of its departments redrafted its community feedback mechanism to make it more accessible for persons with disabilities. Its protection unit initiates most changes and is responsible for monitoring progress in other organizational departments. For example, protection staff will conduct regular site visits to determine whether newly built service facilities are accessible for persons with disabilities and whether persons with disabilities participate in consultation and community meetings.

The organization's donor-recipient partnership with a disability-focused NGO is centred around bringing about change. Thanks to this partnership, staff from different departments at different levels have benefitted from comprehensive training on the collection and analysis of disaggregated data, identification and removal of existing barriers and promotion of the participation and empowerment of persons with disabilities. Furthermore, the disability-focused organization helped draft the action plan on disability inclusion, which formed the basis for a mission-wide, multi-year operational action plan that started in 2020.³²

32 Interview with a United Nations staff member.

However, there is always room for further improvement, even in the most progressive organizations. Research in Cox's Bazar shows that most change happens at the programming level but not within the organizational structures of the organizations themselves. Although organizations are increasingly including persons with disabilities in cash-for-work schemes and income-generation programmes, for example, their compounds are not accessible to persons with mobility restrictions. One respondent explained:

If you look at this compound, it's not friendly for persons with disabilities [...]. I can't figure out why that door opens this way, but the other door opens the other way. Our structural planning for this compound was not good.

Interview 5, representative of a United Nations agency.

Moreover, respondents agreed that until now, organizational-change processes depended on the efforts of just a few individuals. More sustained energy and support is therefore needed to institutionalize disability inclusion within the mission's wider structures:

Right now it's because we're pushing for it [...] but if I go away tomorrow and never come back, will it fall flat? Will other people carry it forward?

Interview with a United Nations staff member.

There is reasonable doubt that all humanitarian actors will continue to pursue the inclusion of persons with disabilities with the same level of enthusiasm. It takes significant time to raise awareness among staff, engage them in training to build their capacity, develop a mission-wide action plan and follow through with its implementation. In dynamic environments, such as Cox's Bazar, time is a scarce resource.

To be most effective, training should therefore be well planned, tailored to the participants' needs and build on their previous knowledge. Training courses often last several days and involve follow-up surveys to assess whether the participants could improve their skills on disability-inclusive humanitarian action. This raises the issue of whether organizations can afford to exempt their staff from their daily tasks to participate in multi-day skills training. Raising awareness among a few line managers is not sufficient; organizations need to ensure that staff from all levels benefit from capacity-building, especially since most staff (particularly those in the field) are unfamiliar with international standards on the inclusion of persons with disabilities and corresponding commitments (which many United Nations agencies have made).³³ One respondent explained:

If we're really going to do this well [...] it needs to be all of us. It can't just be a couple of people hitting the drum and making noise about it. It really needs to be all of us.

Interview with a United Nations staff member.

However, many United Nations agencies and NGOs already struggle with everyday demands in the camps and host communities, and some managers perceive disability mainstreaming as an additional burden in an already challenging environment (interviews 5 and 13).

Further complicating organizational change is the fact that competition for qualified staff is high and many organizations in Cox's Bazar struggle with frequent staff rotations. Staff training will only have a lasting impact if the trained individuals stay in their jobs for a substantial amount of time. At present, expatriates rarely stay longer than a year, if at all, and qualified Bangladeshi nationals usually look for attractive job opportunities in organizations that pay higher salaries or offer additional benefits. The level of funding and overall spending on administrative and overhead costs varies among United Nations agencies (NewAge, 2019) and some respondents stated that they had lost qualified staff to organizations with more

³³ Interview 13.

decision-making powers in the humanitarian response (interview with a United Nations staff member).

According to two respondents, developing mission-wide, multi-year organizational action plans on disability inclusion is an excellent entry point to mainstream disability within the organizational structures. So far, however, no United Nations mission in Cox's Bazar has developed such a plan and the motivation to create one largely depends on requests from donors and does not intrinsically derive from the organizations themselves. One respondent explained:

The Australians have asked us to develop an operational action plan for gender and for persons with disabilities. This is quite good for us because now we have the impetus to [draft] a mission-wide plan and get everyone involved.

Interview with a United Nations staff member.

The development of a mission-wide action plan requires technical knowledge, good organization and prior planning. United Nations missions that have firm support from their headquarters and employ their own technical experts are therefore best placed to achieve this. Disability inclusion should be part of an organization's regular functioning from the start of a response, otherwise organizations will always be late in implementing disability-inclusion projects and programmes during humanitarian emergencies. Nevertheless, even the most progressive action plan will only have a lasting impact if the organization can ensure its effective implementation. This depends on the organization's capacity to mainstream disability in its own programmes and structures, in addition to its ability to monitor the activities of its implementing partners. According to respondents, despite benefitting from capacity-building on disability inclusion, INGOs and NNGOs had not been proactively monitoring their partners' attempts to include persons with disabilities in their activities at the camp level, indicating that there is room for further improvements in monitoring.

Implementing partners simultaneously complained about the lack of uniform standards in UNHCR and IOM-led camps.³⁴ Different rules and regulations complicate the removal of physical barriers for persons with disabilities and should therefore be harmonized. The literature and responses from respondents in the field indicate that coordination between the two organizations has improved compared with the early phase of the humanitarian response (Sida and Schenkenberg, 2019). However, sustained efforts are still necessary to facilitate smooth coordination and harmonize diverging standards.

Box 4. The Configuration of the Humanitarian Coordination Structure

The configuration of the humanitarian coordination structure in Cox's Bazar is quite unusual. Typically, the United Nations High Commissioner for Refugees (UNHCR) would be the lead agency in the response. However, when the Government of Bangladesh adopted the National Strategy on Myanmar Refugees and Undocumented Myanmar Nationals in 2013, it granted the International Organization for Migration (IOM) a key leadership role. Due to criticism from other agencies, IOM established the Inter-Sector Coordination Group (ISCG) in 2016, which organizes the agencies involved in the Rohingya response into 12 thematic sectors and subsectors, as well as working groups on cross-cutting issues such as Gender in Humanitarian Action, Communicating with the Communities and Information Management and Assessment. This structure largely resembles the cluster approach that was designed in 2005 by the Inter-Agency Standing Committee (IASC) for non-refugee situations (Sida and Schenkenberg, 2019, p. 16). At Cox's Bazar level, the senior coordinator of the ISCG ensures the humanitarian coordination of the overall response, "including liaison with the [Office of the Refugee Relief and Repatriation Commissioner], District Deputy Commissioner and government authorities at *upazila* level" (ISCG, 2020, p. 37).

34 Field notes from 5 February 2020; conversation with a representative from an INGO.

Since late 2017, a senior executive group in Dhaka has supported the work of the ISCG. The group is co-chaired by the IOM Chief of Mission, the United Nations Resident Coordinator and the UNHCR country representative. It provides strategic guidance to humanitarian agencies and liaises with the National Task Force and relevant ministries on sector-specific issues (Ibid., p. 37).

This unusual arrangement grants IOM "a larger than usual implementation role in an overlapping mandate with UNHCR" (Wake and Bryant, 2018, p. 25) and fosters concomitant inter-agency competition, which proved to be particularly detrimental in the early phases of the large-scale refugee crisis. Both IOM and UNHCR assumed responsibilities for different camps, applying different quality standards for service delivery and different, yet overlapping, systems of data collection (Sida and Schenkenberg, 2019, p. 16). Moreover, fragmentation and weak linkages between the agencies' sectors created unfavourable conditions for certain groups of refugees. For example, the site management teams treated the construction of service facilities merely as a technical operation without taking into consideration protection concerns (Ibid., p. 17).

The creation of an enabling environment for persons with disabilities in the camps is also hampered when agencies cannot remodel their service facilities or face a lack of available land. One respondent explained:

It's not easy to change the infrastructure of our service facilities [after government approval]. We are trying to make them a little bit more accessible, but we cannot build a proper ramp. We do not have that much land.

Interview with a United Nations staff member. Note: See also Holloway and Fan (2018, p. 11) and ISCG (2019, p.12).

The lack of land is – at least for some organizations – a particular hindrance to reducing the physical barriers for persons with disabilities in the camps.³⁵ However, it is important not to limit disability inclusion to physical accessibility. Institutional barriers also impact inclusive humanitarian programming. They stem from the configuration of the United Nations coordination structure, with IOM and UNHCR both assuming responsibility for different camp areas, issues with land allocation, the general dynamic environment that leaves little time and room for capacity-building and monitoring, and high staff turnover within the organizations. While some progress has been made, multiple priorities, limited resources and often limited internal capacity on disability inclusion have posed challenges for organizations striving to become more inclusive in their operations. However, all agencies that participated in this study had taken some measures to increase their organizational capacities on disability inclusion, for example through training or appointment of so-called ‘inclusion champions’. Moreover, many United Nations agencies were thinking about ways to adapt some of their survey tools to incorporate the Washington Group Short Set of questions.

Donor-recipient partnerships with disability-focused NGOs offer a great opportunity to support change processes within United Nations agencies. They contribute to awareness-raising and capacity-building and provide support to promote inclusive programming. Nonetheless, the respective agency is ultimately responsible for ensuring disability mainstreaming and inclusive programming, including meaningful participation. Respondents from agencies that displayed a high internal motivation for change at both headquarters level and within the country programme were more positive about and receptive to the support they received from the disability-focused organizations. Regrettably, disability-focused NGOs only have limited capacities to provide training and technical assistance, which forces them to focus on a limited number of agencies and organizational units. Similarly, the period of cooperation between disability-focused NGOs and individual agencies is often too short to have a significant impact on the wider

35 However, the United Nations has a comparatively strong negotiation position with the government and could use it to advocate for the rights of persons with disabilities. As part of the senior executive group, UNHCR, IOM and the United Nations Resident Coordinator are in constant communication with the authorities and can raise pressing issues regarding the inclusion of persons with disabilities.

mission, especially when the agency operates in various sectors and employs thousands of staff members. Therefore, technical and financial support from the global headquarters and a strong motivation among staff members at all levels of the organization remain indispensable for successful inclusion of persons with disabilities in their programming and services.

4.4.2 Non-governmental Organizations and Consortia Projects

Before the influx of refugees, only five INGOs and five NNGOs were working with the Government in Cox's Bazar to support the Rohingya response (ISCG, 2018, p. 69). With the arrival of hundreds of thousands of refugees in late 2017, the number of NGOs in the district rose sharply. In early 2020, at least 54 INGOs and 61 NNGOs were working in ten humanitarian sectors – health, education, logistics, shelter, WASH, nutrition, site management, emergency telecommunications, food security and protection (with the subsectors child protection and gender-based violence) – as well as in six cross-cutting working groups (OCHA, 2020). All organizations participating in this study had a portfolio of several million USD and employed at least 200 staff. The number of expatriates in the international organizations varied from 5 to 10 per cent.³⁶

From the very beginning of the Rohingya crisis, INGOs and NNGOs assumed a key role in providing humanitarian relief either as partners of United Nations agencies or in stand-alone activities with funding from other key donors.³⁷ To enhance the coordination of their activities, they established the Bangladesh Rohingya Response NGO Platform in June 2018, with the Danish Refugee Council as the host organization. The Platform meets on a monthly basis and brings together over 100 local, national and international organizations.³⁸

36 Some INGOs were in the process of localising their staff. By the end of 2020, Save the Children, for example, was planning to employ only Bangladeshi citizens.

37 In 2019, the top ten donors to the response were, in descending order: the United States of America, the United Kingdom, Germany, Australia, Japan, European Civil Protection and Humanitarian Aid Operations (ECHO), Canada, the Thani Bin Abdullah Bin Thani Al-Thani Humanitarian Fund (a foundation established by the ruling family of Qatar), and Sweden (OCHA, n.d.).

38 Interview 8.

Moreover, NNGOs and INGOs increasingly formed consortia to combine and share their expertise, engage in advocacy, or ease heavy administrative processes.

Disability-focused organizations are also involved in consortia projects, which have (so far) been funded by DFID and DFAT. The objectives, number of consortium members, sectors of intervention, geographic coverage, number of beneficiaries, level and length of funding differ from one project to another. Nevertheless, these projects all aim to deliver inclusive humanitarian assistance to the Rohingya refugees (and host communities), while simultaneously mainstreaming disability and strengthening the capacities of the consortium members. One respondent describes the responsibility of its organization in the following way:

Our role is to coordinate the seven partners and then provide technical support to all of them [...]. While we coordinate and provide technical support, our role is facilitative. We facilitate the process. To show them the way and then they drive the vehicles towards achieving that, for protection and inclusion [...]. The partners should be able to identify where the problems are, and work towards addressing them, while we provide them with support.

Interview 14, representative of an INGO.

In concrete terms, this means that disability-focused organizations assist them in inclusion assessments, determine priorities and entry points for inclusion, develop an action plan, provide technical support and build capacities on various aspects through awareness and training sessions; appointment of focal points, who can support ongoing inclusion efforts within these organizations; and reviews of programme tools, including data-collection tools to support disability data collection, analysis and use.³⁹ In one consortium project, mainstream NGOs made sure that newly built WASH facilities were accessible to persons with disabilities. These NGOs identified persons with disabilities before starting the construction

³⁹ Interview 14.

work, involved them in the planning phase, and built latrines close to their shelters, ensuring that they were suitable for their needs (for example, big enough to accommodate a support person). Overall, respondents from mainstream NGOs were content with the cooperation and indicated that thanks to the consortia project, their organizations could make their services more inclusive of persons with disabilities. One respondent elaborates:

Before we started the consortium project, we thought that our clinic was the best. We have no gaps. But when HI visited our clinic, we realized that we really need to make sure that our clinic is accessible for everyone.

Interview 21, representative of an NNGO.

Nevertheless, several challenges hamper the success of the consortia projects and limit the inclusion of persons with disabilities in humanitarian programming. These challenges pertain to a decline in donor funding, gaps in internal organizational processes and structures (for example, working in silos, insufficient sharing of experience and information among different organizational departments, and limited internal capacity and resources to ensure inclusion) and administrative procedures. **This suggests that the inclusion of persons with disabilities requires more than awareness and technical expertise. It also depends on several other factors that may not seem related to disability mainstreaming at first sight.** The following section will discuss these challenges in more detail.

4.4.2.1 Donor Funding

Donors play a critical role in the Rohingya response. In 2019, the United Nations appealed for a total of US\$650 million for the Rohingya emergency response (UNHCR, 2020). Moreover, the World Bank has provided US\$480 million in grants to enable Bangladesh to deal with the Rohingya crisis, adding to the US\$100 million the Government of Bangladesh received from the Asian Development Bank (World Bank, 2020).

However, the total level of funding is hard to determine, since many bilateral donors also channel substantial funds through various United Nations agencies.

Without doubt, these are large sums of money, and compared with other crises worldwide, funding for this emergency was stable in 2017, 2018 and 2019, with almost 70 per cent of the requested funding provided under the Joint Response Plan (The Business Standard, 2020). However, when the crisis entered its third year in 2020, there was a noticeable decrease in funding, and many NGOs had to reduce their services, staff and equipment.⁴⁰ One respondent from an INGO describes the situation in the following way:

Agencies mostly depend on donor funding, and donor funding is reducing day by day. When we started in 2017, we got around US\$300 million for three months, while last year it was more or less US\$350 million for a whole year [...]. So it is reducing day by day.

Interview 10, representative of an INGO.

Although funding alone should not prevent NGOs from mainstreaming their activities, many service facilities require remodelling to become accessible for persons with disabilities and a reduction of funds will inevitably delay the achievement of this objective. Moreover, funding for technical support and staff capacity-building of humanitarian actors is decreasing, which further impedes disability mainstreaming. These findings once more highlight the importance of creating an enabling and accessible environment for persons with disabilities from the very beginning of the humanitarian response. Moreover, and perhaps more importantly than the level of funding, the time frames for project implementation are too short for the NGOs to develop a meaningful vision of how to include

40 The amount of funding made available in 2020 is not yet known. Nonetheless, many NGOs reported that they had to reduce programme costs and camp visits revealed that some organizations had to close down their service centres. World Vision, for example, had closed some of their women-friendly spaces in the camps due to funding shortages.

persons with disabilities into their response. Consequently, some respondents highlighted that they only used data disaggregated by age, gender and disability for reporting purposes but not for programming.⁴¹ An interview partner explains:

In terms of funding cycles, the maximum that you can usually get here at the moment is one year, and that's when you are lucky. This makes it difficult to implement sustainable, long-term activities.

Interview 28, representative of an INGO.

As mentioned, many donors make the participation of persons with disabilities a prerequisite for their funding. Yet, it is puzzling how donors expect mainstream NGOs with little experience to invest in capacity-building of their staff, engage in comprehensive needs assessments, develop disability-inclusive action plans and ensure that the activities under the project are inclusive for all beneficiaries with funding cycles of less than a year. In this light, it is hardly surprising that NGOs often only use disaggregated data for reporting purposes, without really mainstreaming disability into their interventions.⁴² One interview partner elaborates:

Your assessment takes a lot of time, then you have also to organize focus group discussions and involve your beneficiaries, collect their opinion and then you have to think about the [inclusive] design, to develop the design, procure the material [...]. Basically, [doing this] in nine months, it's very challenging.

Interview 22.

41 Interviews 12 and 15; field notes, 4 February.

42 Interview 22, conversation with humanitarian staff (senior management) 4 February 2020; focus group discussion.

Donors should therefore recognize that field staff needs time to develop the skills to collect and analyse disaggregated data with the WG-SS and that building knowledge on how to construct accessible facilities requires more than participating in one or two training courses. Increasing the length of the funding cycles to allow sufficient time to build expertise is therefore indispensable if donors want disability mainstreaming to be successful.

4.4.2.2 Administrative Procedures and Internal Organizational Processes

In addition to the above-mentioned challenges, NGOs also encounter other barriers to implementing disability-inclusive programming. Like United Nations agencies, they struggle with an extremely high staff turnover and respondents confirmed that this had a negative impact on the overall success of their consortia projects, including those with disability-focused organizations. Time and time again, new managers would join and quickly leave their jobs, and technical experts from disability-focused organizations constantly had to work with new staff members. This means that they had to provide ongoing awareness and capacity-building to new staff on disability and disability-inclusive programming. Simultaneously, newly employed technical experts from disability-focused organizations, who were not at all familiar with the terms and conditions of the various projects, had to provide technical support to the various project partners in the field.⁴³ This obviously delayed the implementation of several activities.⁴⁴ Clearly, these issues could have been avoided if project managers and technical experts stayed in the field for the entire duration of the projects, which, as mentioned in the previous section, currently do not last longer than a year.⁴⁵ However, sometimes collaboration and implementation issues also stem from the challenge of getting all responsible managers in one room at the same time.⁴⁶

43 Interview 20.

44 Ibid.

45 The problem for staff members is that they usually do not know whether they will be able to continue in their roles once project funding ends. This uncertainty means they need to continuously search for new jobs.

46 Interview 29.

Even if they stay in Cox's Bazar for a substantial amount of time, expatriates are regularly on rest and recuperation (R&R)⁴⁷ and are therefore unable to attend all important project meetings, despite often holding key management positions:

So there [...] was a requirement that each organization has to develop an action plan to mainstream disability into their current programme. But, actually, only officers participated and I think that they came up with something. Yet, I think that it should have come from the management and not from the officers.

Focus group discussion with an INGO.

Some respondents also complained that many humanitarian workers were too busy to follow up on e-mails in a timely manner.⁴⁸ Moreover, it is not easy to secure a long-term visa, and therefore, many positions in the NGOs are vacant, leading those employed in Cox's Bazar to juggle two or more jobs at the same time. This makes it difficult to coordinate activities, schedule training and develop strategic visions of how to include persons with disabilities in programmes and organizational structures.⁴⁹ In one consortium project, training for field staff on how to collect disaggregated data with the WG-SS only took place months after the start of the project. The data collected with this tool were only used for reporting purposes and therefore did not inform project-related activities.⁵⁰

Another factor that prevents disability mainstreaming is the fact that NGOs fail to share their experiences across different departments. Field staff complained about the lack of cohesion within the organizations and claimed that "unless you

47 "‘Rest and recuperation’ (R&R) is a measure to protect the health and well-being of staff and ameliorate work-life balance. It enables international staff to take a break from hazardous, stressful, difficult, and isolated working conditions" (UNHCR, 2018).

48 Interview 29.

49 Interview 22.

50 Interview 22.

were forced to work with other sectors, it would not really happen".⁵¹ Consortia projects only focus on specific sectors and hence only target specific staff in the organizations. This means that practices to include persons with disabilities may improve in one specific sector of the organization but not within another. Clearly, it is impossible for disability-focused organizations to provide training and technical support to all sectors. Instead of working in silos, the management therefore needs to ensure that experiences are shared across different levels and organizational departments. This requires structured and regular exchange, which may be difficult to achieve in such a dynamic environment. Sometimes the consortia projects themselves do not function well and there is little collaboration between consortia members. Some interlocutors explained that organizations that have the same donor failed to establish a common monitoring framework and continue working independently from the other members. This makes it difficult to mainstream disability throughout the consortia. Instead, disability-focused organizations provide a few individual members with technical support on disability-inclusive humanitarian action on an individual basis.

Finally, NGOs also face some bureaucratic hurdles that can result in institutional barriers to disability inclusion. As stated, most INGOs increasingly face difficulties in securing long-term visas for their expatriate staff and many organizations had staff working remotely from their official places of residence outside of Bangladesh.⁵² This implies that these employees cannot physically participate in consortia meetings, training and other relevant activities to foster the inclusion of persons with disabilities. Moreover, regulations for the NGO community create a high administrative workload for the organizations and limit their ability to improve disability-inclusive practices, including reaching out to persons with disabilities.

51 Focus group discussion.

52 See ISCG (2019, p. 13) for more information on this issue.

One respondent mentioned that:

Every six months you have to get a new approval for your activities. And you also have to report every month on these activities to the Government. Moreover, you have to submit a completion report after the six months, in addition to all your other reporting, so it is a lot of administrative work. And if you have a project that is longer than six months, let's say you have a nine-month project, you have to re-apply for permission after six months, even though it is for nine months of funding.⁵³

Interview 31, representative of an INGO.

Since February 2020, the NGO community also have to apply for official RRRC ID cards to access the camps and register their vehicles when entering and leaving the camp areas. There has been considerable miscommunication about the procedures and the application process is time-consuming.⁵⁴ Although there is no direct connection to the inclusion of persons with disabilities, it is clear that such regulations and their concomitant administrative workload take up time that could be spent on capacity-building, technical support, development of disability-inclusive action plans and related activities.

Sometimes NGOs also experience delays in the approval of their interventions, which can cause implementation to be delayed and work to be rushed. In the process, inclusion is sometimes overlooked. This also affects consortium projects with disability-focused NGOs.

53 It is important to note that some organizations mention that the reporting requirements of donor organizations can be more cumbersome.

54 Field notes, 19 January 2020.

One interview partner elaborated:

Officially, the consortium project was supposed to start in April. But in reality, it started in June. However, only one INGO managed to start in June. The other organizations of the consortium struggled with government approval issues and started implementing activities in October/November last year. One INGO is still not on board due to not having government approval [...]. So right now, they participate in the working group meetings and steering committee meetings and take part in decision-making, but they will only start field level implementation, I think, by the end of January.

Interview 10, representative of an INGO.

It is therefore crucial that all NGOs are well prepared and submit their application form as soon as possible so that their projects can be approved on time.⁵⁵

This overview of government regulations for NGOs is by no means exhaustive and, as mentioned, with the outbreak of the COVID-19 pandemic in early 2020, many humanitarian and human rights organizations have criticized the Government of Bangladesh for restricting humanitarian activities in the camps (Human Rights Watch 2020a; Human Rights Watch 2020b; Reliefweb 2020). These administrative procedures and regulations hamper ongoing activities and limit the time that NGOs can invest in capacity-building of their staff and developing inclusive action plans that can be applied across all their operations.

Overall, NGOs in Cox's Bazar recognize the importance of including persons with disabilities in humanitarian action. All respondents were positive about the cooperation with HI, CBM or CDD and the technical support they received within the framework of the consortia projects. However, this section shows that NGOs encounter many obstacles that prevent them from systematically including persons

⁵⁵ Conversation with staff from a disability-focused NGO, 22 October 2020.

with disabilities in their programmes and organizational structures. While NGOs started collecting disaggregated data, made efforts to build accessible latrines and service points, and even developed action plans for specific sectors, they continue to lack a clear vision of how they will become inclusive. The reasons are manifold but the lack of time due to short funding cycles and a high administrative workload, as well as considerable turnover of international staff at management level, represent the biggest obstacles for a strategic approach. This also applies to disability-focused organizations, which also struggle with visa applications, recruitment of qualified staff and limited time and resources. Problems in disability-inclusive humanitarian action will persist until these structural issues are resolved.

Box 5. The Government of Bangladesh and the Rohingya Response

The Government of Bangladesh is involved in all aspects of the Rohingya refugee response and is also responsible for its overall coordination. At different levels of governance, various state actors maintain close oversight over the humanitarian activities implemented in each sector. At the Dhaka level, the Ministry of Foreign Affairs chairs a National Task Force that comprises 29 ministries and entities (Inter-Sector Coordination Group [ISCG], 2019, p. 53). The Task Force was established in 2013 in the context of passing the National Strategy on Myanmar Refugees and Undocumented Myanmar Nationals and gained significance with the arrival of hundreds of thousands of Rohingya in Bangladesh in late 2017. The National Task Force is responsible for determining the refugee policy and takes strategic decisions in this regard.⁵⁶

In Cox's Bazar, the Office of the Refugee Relief and Repatriation Commissioner (RRRC), a powerful agency under the Ministry of Disaster Management and Relief, has many responsibilities, including managing and overseeing the refugee population (ISCG, 2020, p. 39). It chairs monthly meetings of the Sector Coordinators and the Site Planning Task Force, and convenes the monthly law and order meeting of the law enforcement and security agencies population (Ibid., 2020, p. 38).

⁵⁶ In January 2020, for example, it lifted some of its restrictive policies and allowed Rohingya children to receive formal education in Bangladesh.

It also maintains oversight of all camp visits, issues camp passes to humanitarian staff and visitors and registers all vehicles entering and leaving the camp areas. Moreover, the RRRC gives final approval of all activities that humanitarian actors wish to implement in the camps. At field level, the Camps-in-Charge (CiC) lead the coordination of activities in the 34 designated camps and chair regular coordination meetings. The District Deputy Commissioner leads the civil administration in Cox's Bazar and the response to the Bangladeshi host communities (Ibid., p. 38). All humanitarian projects require the approval of the CiCs or the District Deputy Commissioner before they can be implemented.⁵⁷ The basis on which CiCs allow or refuse the implementation of a particular project in the camp under their supervision is not always clear.⁵⁸

Many stakeholders acknowledge the Government of Bangladesh for its efforts and investments to allocate land to the Rohingya, maintain security and order in the Cox's Bazar region and upgrade the road network to facilitate the distribution of essential goods and services. Nevertheless, government supervision of the humanitarian response and its rules and regulations create a high administrative workload and make non-governmental organizations (NGOs) rather hesitant to share their criticisms in official statements because they fear this may further constrain their operations.⁵⁹

However, in October 2020, 27 international non-governmental organizations (INGOs) released an official statement in which they urged United Nations Member States, the donor community, United Nations agencies and leadership to address the root causes of displacement, protect the human rights of the Rohingya refugees and enable unfettered humanitarian access (Reliefweb, 2020).

57 Interview 16, representative of an INGO.

58 Some respondents feel that "for different camps there are different types of rules, created by the respective CiCs in charge" (Interview with a representative of an NNGO, 2 February 2020). However, there are no separate rules and regulations for different camps. There are instances where CiCs from different camps request additional documents and clarifications, which can result in confusion among the implementing organizations.

59 Conversation with a representative of an INGO, 6 February 2020.

4.4.3 Age and Disability Working Group

In 2018, HI, CBM, CDD and HelpAge International established the ADWG to promote the inclusion of persons with disabilities in established humanitarian coordination structures. In the first two years of its existence, the ADWG "has been paddling along"⁶⁰ and did not have any tangible influence on the larger humanitarian response. Some individual initiatives of its members had an impact: for example, with support from CBM and CDD,⁶¹ the WASH sector developed common standards on the construction of accessible latrines. However, the ADWG had an overall lack of strategic vision and of a common approach to advocating on behalf of older persons and persons with disabilities.

This changed in 2019, when the ADWG began to take a structured approach. It changed its name from the 'Age and Disability Task Force' to the 'Age and Disability Working Group', developed terms of reference, which specify objectives, activities, membership and reporting procedures (although these are still under revision), and hired a coordinator to ensure smooth coordination between its members and with external organizations. In early 2020, the group also established a formal collaboration framework with the Protection Working Group, under the leadership of UNHCR, and agreed on a joint action plan for its members, which outlines the main tasks to advocate on the inclusion of older persons and persons with disabilities.

In 2020, these efforts delivered their first results in the humanitarian response in Cox's Bazar. Together with the Protection Working Group, the ADWG published a joint COVID-19 **Guidance Note** on making the response age- and disability-inclusive. The Guidance Note highlights factors that put older persons and persons with disabilities more at risk of contracting the virus and provides humanitarian actors with recommendations on mitigating these risks (ADWG and Protection Working Group, 2020). Moreover, together with the Protection Working Group and the REACH Initiative, the ADWG started working on a joint **needs assessment**.

⁶⁰ Conversation with humanitarian staff (senior management), 4 February 2020.

⁶¹ Interview 20.

"It relies on quantitative and qualitative data collection methods and has the following objectives: 1) to further the response-wide understanding of the safety and dignity of persons with disabilities across all age groups; 2) ensure meaningful access to multi-sectoral services and assistance; 3) foster participation and empowerment within community and humanitarian spaces; 4) consider the specific requirements of persons with disabilities in disaster preparedness and risk reduction; and 5) capture the voices and experiences of persons with disabilities and older persons in a holistic and dignified fashion. The ADWG provides training to enumerators and technical support to the project team to ensure that the methodology, tools, data-collection process, analysis and use of data is inclusive to all persons with disabilities, including hard-to-reach groups, such as deaf persons and persons with autism. Results of the needs assessment are expected for the second half of 2020" (Funke, 2020, p. 32).⁶² In 2020, the ADWG is also working on a study of the World Food Programme food voucher system and how it can become more inclusive for persons with disabilities.⁶³

Without doubt, these are steps to mainstream disability throughout the response and more efforts are necessary to ensure that all clusters ensure the inclusion of persons with disabilities in their interventions. The ADWG can make a vital contribution towards achieving this. At this point, the influence of the ADWG on the humanitarian coordination structures still heavily depends on the Protection Working Group and its lead agency UNHCR. Consequently, this relationship, though important, runs the risk of making the ADWG strongly dependent on UNHCR and the Protection Working Group Task Team (which consists of six influential agencies and NGOs).⁶⁴

62 See also REACH Initiative (2020), p. 5.

63 Skype conversation with staff from a disability-focused NGO, 22 October 2020.

64 Field notes, 26 January and 4 February. The task team is a technical expert group. During regular meetings, a selected group of organizations discusses policy issues and issues pertaining to emergency preparedness. Members of the task team are UNHCR, UNICEF, IOM, United Nations Population Fund, HI, the Danish Refugee Council, Oxfam, World Vision, BRAC, Caritas Bangladesh and ActionAid (Protection Working Group, 2019). In many humanitarian contexts, working groups that promote the inclusion of persons with disabilities fall under the broader umbrella of protection mainstreaming, which is spearheaded by UNHCR. Therefore, this collaboration is not unusual and the risk that these groups will strongly depend on UNHCR is not unique to Cox's Bazar. Nonetheless, it is worth highlighting that, ultimately, disability has to be mainstreamed in all sectors as part of the broader protection mainstreaming approach.

In fact, UNHCR largely determined the terms and conditions of their cooperation with ADWG, and initially even considered revising its terms of references to fit the expectations and needs of the Protection Working Group. Eventually, UNHCR decided to ease "this long and heavy process" and developed a list of nine objectives to be included in the terms of references of the ADWG's coordinator, who is supposed to act as a bridge between UNHCR and the working group.⁶⁵ The coordination framework between the ADWG and the Protection Working Group contains many of these ideas, demonstrating UNHCR's strong role in laying the groundwork for their cooperation.

Yet, until 2020, UNHCR did not have a strong focus on disability inclusion. The 2019 Joint Government-UNHCR registration exercise, for example, relied on a binary 'yes/no' question to estimate the proportion of persons with disabilities in the camps instead of the WG-SS. It is therefore hardly surprising that the survey found that merely one per cent of the refugees has a disability, a figure that clearly contradicts the 2011 study, which finds that approximately 15 per cent of any population are persons with disabilities (WHO and World Bank, 2011).

In the long term, the ADWG strives to operate more independently and also to systematically involve more OPDs and other self-help groups from the Cox's Bazar district. For the time being, close cooperation with the Protection Working Group is critical for the ADWG and its ability to exert influence on the humanitarian response. This is even more the case in light of the heavy workload of the ADWG chairs and co-chairs. Simultaneously, UNHCR and other agencies greatly benefit from the ADWG's expertise.

Ultimately, the success of the ADWG depends on its visibility in the different sectors and their respective subgroups and on a clear and realistic strategy to incorporate persons with disabilities into the sectors' policies. At this point, it is still too early to evaluate the impact of the ADWG on the humanitarian response.

⁶⁵ Conversation with UNHCR staff member.

However, it is clear that through close cooperation with the Protection Working Group, as well as other key agencies, the ADWG can position itself as a fervent supporter of age and disability inclusion, increase its visibility in the sector meetings, and meet the growing demands of technical support on disability-inclusive humanitarian action beyond the individual contributions of its members in various donor-recipient partnerships and consortia projects. In summary, the ADWG can offer valuable guidance, information and good practice examples that will be relevant for all humanitarian agencies involved in the response. Therefore, it can supplement individual partnership projects and bundle the expertise of key disability-focused NGOs that are active in different camp areas and host communities.

Box 6. Development of the Age and Disability Working Group

In 2018, the Age and Disability Working Group (ADWG) started as a loosely coordinated group of four age- and disability-focused organizations without a clear action plan. In 2019, these organizations started discussions with the Protection Working Group on positioning the ADWG as a part of the Protection Working Group. Moreover, other organizations increased their engagement with the ADWG. In 2019, the ADWG managed to secure funding for a full-time coordinator and a consultant from an organization of persons with disabilities (OPD). To streamline their work, the ADWG members also developed a joint action plan and successfully started collaborative work in some humanitarian sectors (water, sanitation and hygiene, education, health, and protection). The water, sanitation and hygiene sector, for example, developed easy-to-access guidelines, with support from the ADWG, that were approved in 2020. Some organizations also benefitted from joint training courses with ADWG members. In 2020, the ADWG member organizations also formalized their cooperation with the Protection Working Group, which further increased demands from mainstream actors for technical support and capacity-building. Simultaneously, mainstream actors became involved in the work of the ADWG. While some joined as active members (for example, the International Committee of the Red Cross), others regularly attended

the meetings (for example, the United Nations Development Programme (UNDP) and Save the Children). At present, the ADWG is revising its terms of reference to further improve the group's effectiveness and publishes a monthly newsletter to inform the humanitarian community in Cox's Bazar about its activities, present good practice examples and advocate for a more inclusive response. All these steps have contributed to its recognition as a firm advocate of age and disability inclusion in Cox's Bazar.



5. Conclusions

This study centred on three research questions, aiming to 1) shed light on how humanitarian actors mainstream disability, 2) identify the factors that challenge the inclusion of persons with disabilities in the refugee camps and host communities, and 3) evaluate the contribution of strategic partnerships and NGO consortia to a more inclusive humanitarian response. This final part of the report will present the main findings of this study and present recommendations to donors, the Bangladeshi authorities, international humanitarian organizations, national and local NGOs, persons with disabilities, and researchers.

5.1 Main Findings

In spite of the CRPD, the Humanitarian Disability Charter, and international standards and guidelines, humanitarian actors overlooked the rights and specific requirements of persons with disabilities during the early phase of the crisis in 2017 and 2018, contributing to the marginalization and exclusion of persons with disabilities. Since 2019, this has gradually changed and many humanitarian actors in Cox's Bazar recognize the importance of mainstreaming disability in their operations. Nonetheless, significant gaps remain in protection and assistance, which result from a lack of comprehensive, reliable and disaggregated data; a lack of participation of persons with disabilities in humanitarian programming; and numerous institutional, attitudinal and environmental barriers. Disability mainstreaming needs to be included in humanitarian activities in the camps from the get-go, otherwise humanitarian actors will always be playing catch-up.

To close these gaps and ensure the inclusion of persons with disabilities in the humanitarian response, United Nations agencies, as well as INGOs and NNGOs, intensified their cooperation with disability-focused NGOs. They entered into partnerships or formed consortia projects to build their organizational capacity on disability-inclusive humanitarian action. Moreover, the ADWG now promotes age and disability inclusion throughout the humanitarian response. Two main factors account for these changes. First, more and more donors demand clear disability-inclusive deliverables from their implementing partners.

Second, the beneficiaries themselves increasingly raise awareness of the concerns of persons with disabilities in their interactions with humanitarian staff.

This study shows that the inclusion of persons with disabilities remains a long-term undertaking. Many organizations have just started building their capacity on disability inclusion. Although there has been some level of commitment from numerous humanitarian actors by signing the Charter on Inclusion of Persons with Disabilities, there is still no systematic approach to disability-inclusive humanitarian action. Instead, organizational change still largely depends on the efforts and commitment of a few individuals. Moreover, the local dynamics inhibit the development of holistic, long-term approaches to disability inclusion. Although Cox's Bazar is a comparatively safe context for humanitarian agencies, short funding cycles, frequent staff rotations, procedures that entail a high administrative workload, and limited information-sharing among organizations and within organizations impede disability-inclusive programming. Furthermore, and due to these challenges, capacity-building and technical support within strategic partnerships and consortia projects with disability-focused NGOs have so far focused on certain sectors and targeted a limited number of humanitarian staff. The international legal documents are relatively new and not well-known among mainstream humanitarian actors, especially at field level. It is therefore hardly surprising that humanitarian organizations lack a systematic approach to ensuring the inclusion of persons with disabilities at the organizational and programming levels. Such a systematic approach should be taken in all activities throughout the humanitarian organizational system.

Compared with ad hoc approaches, systematic and targeted capacity-building as well as technical assistance within strategic partnerships can fundamentally contribute to disability inclusion. Mainstream organizations that maintained a donor-recipient partnership or were part of a consortium project with a disability-focused NGO reported that they had changed their methods of data collection, and now used the WG-SS to inform programming and monitoring. Moreover, they deliberately involved persons with disabilities in their interventions, for example, in cash-for-work programmes and focus group discussions. In addition, they considered ways of reducing environmental barriers and making their services more accessible. Nonetheless, it is important to highlight that disability-inclusive humanitarian action involves more than just addressing accessibility.

It is equally important to promote meaningful participation and empowerment of persons with disabilities, and to remove institutional and attitudinal barriers within the communities and among humanitarian staff.

The main advantage of these partnerships is that mainstream actors can rely on technical support from disability-focused NGOs beyond a single training session. They can build on the expertise of these NGOs for the whole period of the project. Disability-focused NGOs encourage the development of disability-inclusive action plans, oversee the implementation of these plans, review monitoring reports, and support the documentation of case studies and good practice reports.

In addition to these partnerships and consortia, the ADWG, in close cooperation with the Protection Working Group, strives to identify priority protection concerns, create public awareness, cooperate with the Government on mainstreaming issues, participate in information management and data set collection, and in short, ensure that disability issues are mainstreamed across sectors and subsectors. However, it is still too early to evaluate the long-term impact of these mainstreaming efforts.

While multiple factors influence whether humanitarian organizations become disability-inclusive, longer-term programming cycles would enable agencies to more systematically incorporate disability inclusion into programme planning. Other key factors include the absence of OPDs in the Cox's Bazar district and the prohibition of forming organized groups in the camps, which impede the empowerment of persons with disabilities and their participation in programme activities.⁶⁶ Although organizations increasingly involve them in community meetings, focus group discussions and projects, and encourage the establishment of loosely connected self-help groups, persons with disabilities do not participate in the humanitarian response in a structured manner. This must change. Humanitarian organizations must enhance their communication and cooperation across their different departments to become more disability-inclusive. This should involve exchanging information, data and experiences in disability-inclusive humanitarian action with other organizations.

⁶⁶ However, since data collection ended, informal disability committees have formed in the camps.

Inclusion should not be treated as an add-on. All organizations should integrate it into their day-to-day operations as a strategic issue, so that they are better prepared to deal with new crises.

5.2 Recommendations

To further enhance the capacities of mainstream actors in disability-inclusive humanitarian action and ensure the full protection of persons with disabilities in the humanitarian response, this study arrives at the following recommendations.

5.2.1 Donors

Although changes to funding policies have been incorporated into the Grand Bargain, launched during the 2016 World Humanitarian Summit, actual change has been slow. Since 2019, several donors, including the German Federal Foreign Office, encourage NGOs to form consortia projects to systematically build their capacities on inclusion. However, at present, humanitarian organizations too often use gender-, age-, and disability-disaggregated data for reporting purposes only. Clearly, funding cycles of less than a year are insufficient to bring about fundamental change. Conducting and participating in training sessions, organizing inclusion audits, collecting and analysing disaggregated data on disability, designing accessible facilities, procuring materials, negotiating with the authorities and overseeing the implementation of these projects can be demanding for organizations, which grapple with high staff turnover and have little experience in disability-inclusive humanitarian action. Longer funding cycles will enable long-term planning and activities. Donors should therefore:

- make disability inclusion a pre-condition for funding
- recognize inclusive humanitarian action as a system-wide issue
- ensure sufficient and reliable long-term funding
- continue advocating for a return to Myanmar and ensure that the rights of persons with disabilities are respected during repatriation, once this becomes possible.

5.2.2 *Bangladeshi Authorities*

The initiatives, which the Government of Bangladesh has taken to become more inclusive, could be built upon. The authorities could:

- facilitate longer-term programming for humanitarian actors
- facilitate and support the provision of humanitarian services and apply common standards consistently across all camps
- encourage the establishment of self-help groups among the Rohingya with disabilities to promote meaningful participation
- continue advocating for a return to Myanmar and ensure that the rights of persons with disabilities are respected during repatriation, once this becomes possible.

Moreover, the authorities could:

- reduce barriers for and encourage the inclusion of persons with disabilities in the Cox's Bazar district, in consultation with humanitarian actors and persons with disabilities themselves
- increase the awareness of the local authorities on the rights of persons with disabilities and the obligations under the CRPD
- collect and publish reliable data on persons with disabilities and use them as a basis for the protection of persons with disabilities in the Bangladeshi host communities.

5.2.3 *International Humanitarian Organizations*

Although humanitarian organizations increasingly reach out to and involve persons with disabilities in focus group discussions and cash-for-work projects, persons with disabilities still do not participate in all aspects affecting their lives.

Humanitarian organizations should therefore:

- promote the meaningful participation of persons with disabilities in all stages of their programmes, which will also entail encouraging the establishment of OPDs in Cox's Bazar.

Some humanitarian organizations have started to collect and analyse data disaggregated by age, gender and disability. However, persons with disabilities are not systematically considered in the annual needs assessment and in large-scale registration exercises. Humanitarian organizations should:

- accelerate their efforts to close significant data gaps
- make disaggregated data available for all relevant stakeholders
- ensure that data form the basis for further project planning and implementation and are used for more purposes outside of donor reporting.

So far, and as mentioned above, disability-inclusive humanitarian action often depends on the efforts and commitment of a few individuals. However, it is crucial that inclusion becomes part and parcel of the organizations' work from the beginning. Indeed, this research shows that it is very difficult and costly to make changes in the infrastructure and service provision later on. Moreover, interviews with United Nations staff suggest that agencies that had substantial support from their headquarters were more advanced in promoting the inclusion of persons with disabilities. Humanitarian organizations should:

- consider the specific requirements of persons with disabilities from the very beginning of every intervention
- show firm commitment to disability inclusion, develop an organization-wide diversity policy to promote inclusion in all countries of operation and institutionalize disability mainstreaming within the organization's structures
- make sure that compounds and crucial infrastructure are accessible for persons with disabilities

- focus on capacity-building at all levels and sectors of the humanitarian response, including the headquarters.

The main focus has so far been on the needs and vulnerabilities of the refugees, while those of the host communities have been largely neglected. The humanitarian community should therefore:

- increase assistance and services for particularly vulnerable and marginalized groups, including persons with disabilities in the host communities, to mitigate protection risks and inter-community tensions between host populations and the refugees.

Humanitarian organizations are also in competition for funding and qualified staff. To learn from one another's experience in inclusive humanitarian action, organizations should:

- engage in knowledge-exchange and information-sharing to identify good practices that can inform future planning and implementation.

Lead organizations, notably UNHCR and IOM, function as role models for others. UNHCR in particular has to build up its internal capacity and ensure that all staff at all levels of the organization promote the inclusion of persons with disabilities. UNHCR should:

- step up its efforts to mainstream disability, as it is not sufficient to rely solely on the cooperation framework with the ADWG.

Both UNHCR and IOM should further:

- enhance their coordination and cooperation on disability mainstreaming and develop common standards in the camps, as this will also facilitate the work of the NGOs, which work as implementing partners for both agencies.

5.2.4 National and Local Non-governmental Organizations

International organizations still dominate the humanitarian coordination structures, which sometimes impedes long-term planning because international organizations have difficulties securing visas for their expatriate staff and expats only stay in the field for a short period of time. Moreover, some respondents believe that national and local organizations are more flexible than international ones and can more easily mainstream disability into their organizational structures because standardized procedures of aid delivery have not yet been established. National and local NGOs should:

- systematically build up their capacities on inclusive humanitarian action
- make sure that they gradually assume a leading role in the response.

5.2.5 Persons with Disabilities

Persons with disabilities have been marginalized in society and in the refugee response. It is vital that they:

- familiarize themselves with their rights
- voice and claim their preferred methods of inclusion
- increase their confidence as active contributors in society and organize themselves either informally in disability committees or in self-help groups and OPDs.

5.2.6 Further Research

Systematic research on disability-inclusive humanitarian action is scarce. Consequently, a follow-up study in East Africa within the framework of this project will allow for more comparative research on disability-inclusive humanitarian action.

Moreover, researchers should:

- conduct more and longer-term ethnographic and impact studies on disability-inclusive humanitarian action
- document the perceptions of persons with disabilities on their role in humanitarian action
- identify more good practices and lessons learned from research in Cox's Bazar and other humanitarian crises responses
- develop and carry out a comprehensive review of the degree of compliance with and implementation of the CRPD, the Humanitarian Disability Charter, the IASC Guidelines, the Humanitarian Inclusion Standards and related documents, entailing, at least, a quantitative staff study of disability-focused organizations, OPDs, and other humanitarian organizations at the international level, as well as long-term field studies to understand national and local perceptions and capacities.



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