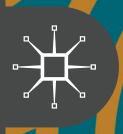

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Disability Inclusion in Humanitarian Crises

Robust Human Rights Norms?

Carolin Funke · Dennis Dijkzeul

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Carolin Funke
TU Dortmund University
Dortmund, Germany

Dennis Dijkzeul
Ruhr-University Bochum
Bochum, Germany

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Preface

Armed conflicts and natural disasters disproportionally affect persons with disabilities. However, persons with disabilities remain insufficiently included in the operations of humanitarian organizations. This book studies disability inclusion in humanitarian crises. It explores how activists and international organizations have promoted a rights-based understanding of disability in international law and the extent to which this understanding has gained acceptance in humanitarian policy and practice. We have engaged with donors, United Nations (UN) agencies, non-governmental organizations (NGOs), and persons with disabilities and their representative organizations to gain a deeper understanding of the dynamics of disability inclusion norms and organizational action at all levels of global governance.

Our book is an outcome of the "Leave No One Behind!" project's second phase, which was jointly implemented by Handicap International (HI), Christian Blind Mission (CBM) and the Institute for International Law of Peace and Armed Conflict (IFHV) between 2018 and 2021. Taking its title from the 2030 *Agenda for Sustainable Development* and the 2016 World Humanitarian Summit, the "Leave No One Behind!" project series has focused on mainstreaming disability in humanitarian action through capacity development, applied research, and awareness raising since 2016.

Our book is intended for persons with disabilities, their caregivers, members and staff of organizations of persons with disabilities (OPDs),

public professionals, staff from the UN agencies and NGOs, as well as scholars from International Relations (IR), disability, humanitarian, and development studies. We focus more on humanitarian crises than on development because protracted crises have become increasingly common. Previous models of a linear transition from humanitarian action to development cooperation have become obsolete with development interventions and humanitarian action often occurring simultaneously.

We are thankful for the comments on earlier drafts by our International Law colleagues, especially Maximilian Bertamini and Benedikt Behlert, as well as for those by an anonymous reviewer. We are also grateful for the tremendous support of our project partners. Their assistance with providing gray literature, facilitating research on the ground, and offering feedback on earlier drafts, while respecting our academic independence, has been invaluable. Particularly, we would like to thank Haakon Spriewald, Ulrike Last, Sabrina Ebert, and Oliver Wiegers. Of course, we extend our appreciation to the editors for their insightful comments that enhanced the book's quality.

We also would like to thank our interview partners, who generously gave their time despite busy schedules. All interviewees provided informed consent, and their identities remain confidential. The German Federal Foreign Office's funding made this research and the open-access publication possible.

We hope that this book will contribute to a better understanding of the challenges faced by, and capacities of, persons with disabilities in humanitarian crises and how humanitarian organizations respond to them.

Any mistakes, of course, remain our own responsibility.

Bochum, Germany
April 2024

Carolin Funke
Dennis Dijkzeul

About This Book

With the 2006 Convention on the Rights of Persons with Disabilities, a new normative understanding of diversity and disability took hold: persons with disabilities were no longer seen as objects of charity but as human rights holders who claim and deserve respect and equality. Nevertheless, persons with disabilities continue to experience heightened protection risks in humanitarian crises. Usually, they can barely access essential services and claim their rights. Combining the innovative norm cluster approach and multi-level analysis, this book explores how the rights-based understanding of disability has evolved in international law and to which extent it has gained acceptance in humanitarian policy and practice. Although donor governments and humanitarian actors have institutionalized a rights-based understanding of disability at the international policy level, only a few have precise inclusion strategies. This delays implementation on the ground and challenges the robustness of the disability inclusion norm cluster.

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About the Authors

Carolin Funke is an expert in disability inclusion and internal displacement. She currently works at TU Dortmund University and is a research affiliate at the Refugee Law Initiative, University of London. Before, she was a postdoctoral researcher at the Institute for International Law of Peace and Armed Conflict (IFHV) at Ruhr University Bochum in Germany and a research fellow at the Institute of Security and Global Affairs, Leiden University. She has conducted extensive field research in Georgia and Cox's Bazar, Bangladesh. Her latest book *Durable Solutions: Challenges with Implementing Global Norms for Internally Displaced Persons in Georgia* was published in 2022.

Dennis Dijkzeul is a professor of conflict and organization research at the School of Social Sciences and the Institute for International Law of Peace and Armed Conflict at Ruhr University Bochum. He was the founding director of the Humanitarian Affairs Program at the School of International and Public Affairs of Columbia University in New York. He has conducted research projects on humanitarian crises and responses in the DRC, Guatemala, Uganda, South Sudan, Nigeria, and Afghanistan, and has worked as a consultant for UN organizations and NGOs. His main research interests concern the management of international organizations (UN, NGOs, and diaspora organizations) and their interaction with local actors in humanitarian crises. His latest books are *The NGO Challenge for International Relations Theory* (with William DeMars), *The New*

Humanitarians in International Practice: Emerging Actors and Contested Principles (with Zeynep Sezgin), *Diaspora Organizations in International Affairs* (with Margit Fauser), and *International Organizations Revisited: Agency and Pathology in a Multipolar World* (with Dirk Salomons).

Abbreviations

ADCAP	Age and Disability Capacity Programme
ADDC	Australia Disability+Development Consortium
AUD	Australian Dollar
CBM	Christian Blind Mission (Christoffel Blindenmission)
CERF	Central Emergency Response Fund
CHS	Core Humanitarian Standard
CRPD	Convention on the Rights of Persons with Disabilities
DFAT	Department of Foreign Affairs and Trade (Australia)
DFID	Department for International Development (United Kingdom)
ECHO	Directorate General for European Civil Protection and Humanitarian Aid Operations (European Union)
EU	European Union
FCDO	Foreign, Commonwealth, and Development Office (United Kingdom)
GFFO	German Federal Foreign Office
GLAD	Global Action on Disability
HI	Handicap International/Humanity & Inclusion
HIES	Household Income and Expenditure Survey
HNO	Humanitarian Needs Overview
HNRP	Humanitarian Needs and Response Plan
HRP	Humanitarian Response Plan
IASC	Inter-Agency Standing Committee
ICRC	International Committee of the Red Cross
IDA	International Disability Alliance
IDC	International Disability Caucus
IDDC	International Disability and Development Consortium

IFRC	International Federation of Red Cross and Red Crescent Societies
IHL	International Humanitarian Law
IOM	International Organization for Migration
IR	International Relations
IRC	International Rescue Committee
ISCG	Inter-Sector Coordination Group
JICA	Japan International Cooperation Agency
LGBTQI+	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning and Intersex plus
MSF	Médecins Sans Frontières
NGO	Non-Governmental Organization
OCHA	United Nations Office for the Coordination of Humanitarian Affairs
ODA	Official Development Assistance
OECD-DAC	Organization for Economic Cooperation and Development – Development Assistance Committee
OFDA	Office of Foreign Disaster Assistance (United States)
OPD	Organization of Persons with Disabilities
UK	United Kingdom
UN	United Nations
UNHCR	United Nations High Commissioner for Refugee
UNICEF	United Nations Children's Fund
UNSC	United Nations Security Council
UNSSC	United Nations System Staff College
USA	United States of America
USAID	United States Agency for International Development
USD	United States Dollar
WFP	World Food Programme
WG-SS	Washington Group Short Set on Functioning
WHO	World Health Organization

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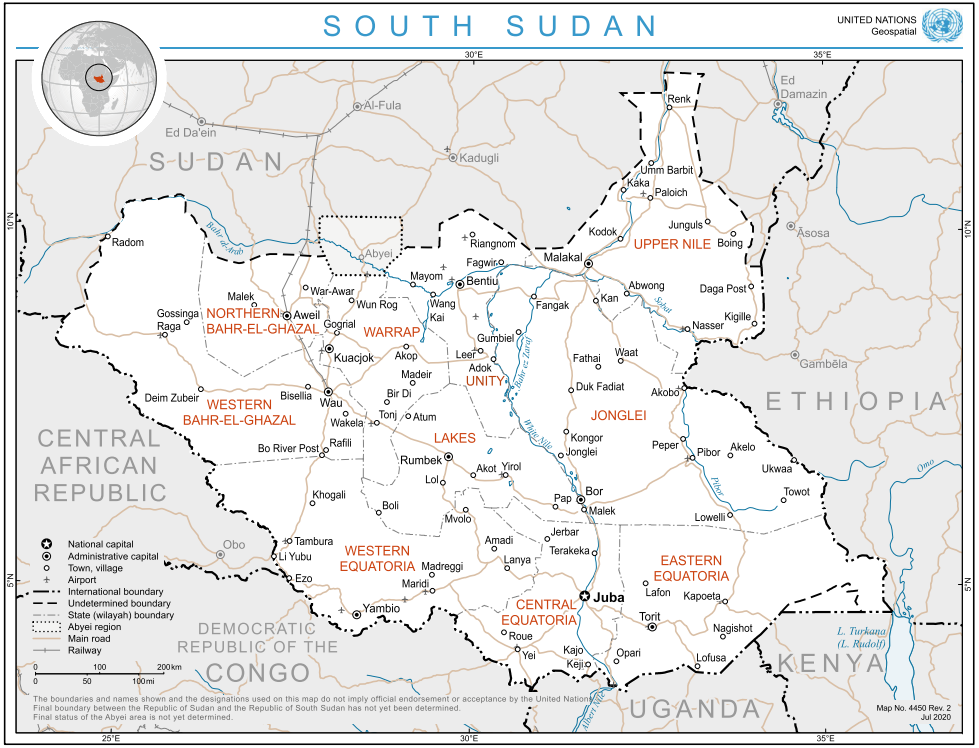
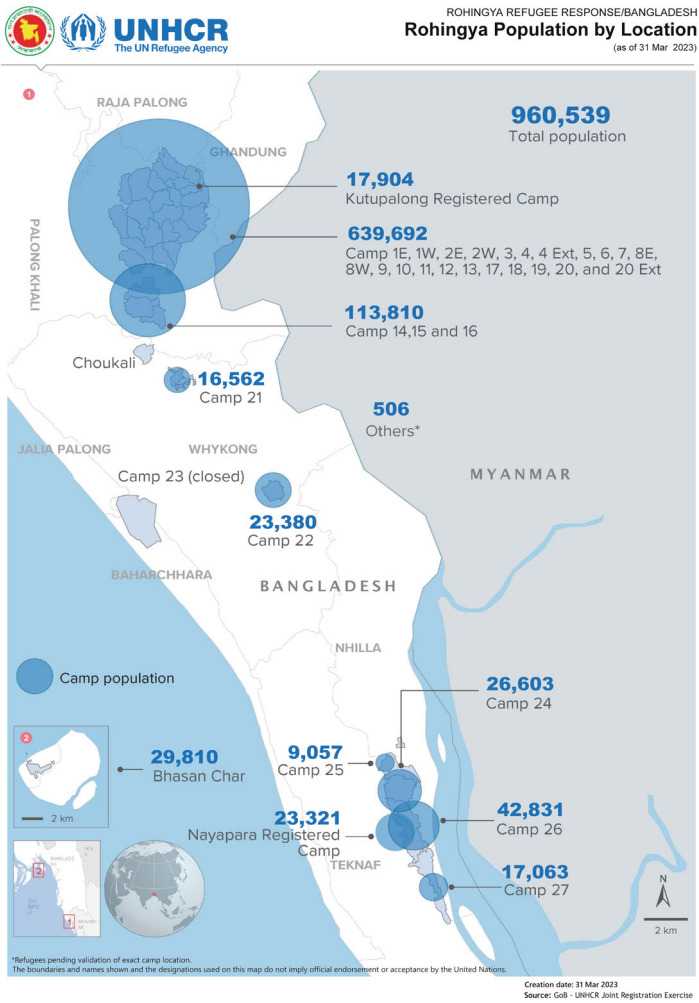


Map 1 South Sudan © United Nations, Map No. 4450 Rev. 2, July 2020



Map 2 Rohingya Refugee Response/Bangladesh ©UNHCR

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CHAPTER 1

Introduction

Abstract The introduction highlights the challenges faced by persons with disabilities during humanitarian crises and the frequent neglect of their needs and abilities. It also addresses the main international norms established to support them. Following this, the introduction discusses the importance of examining the development of disability norms at different levels of global governance. It then presents the book's central research question and main argument, and concludes with an outline of the book's contents.

Keywords Persons with disabilities · Humanitarian crises · Global governance · Inclusion · Human diversity · Sociology of law

1.1 Introduction

The introduction describes the plight of persons with disabilities in humanitarian crises and the lack of attention to both their needs and capacities. It highlights the tough and often neglected challenges that persons with disabilities face, particularly those related to escaping from danger and accessing protection and services. Moreover, it discusses the

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relevance of studying the evolution of disability norms in global governance and presents the central research question, as well as the main argument of the book. It also includes an outline of the book's contents.

1.2 Background: Disability and Diversity in Humanitarian Crises

Approximately 16% of any population are persons with disabilities (WHO, 2022, 2–3). In war-torn countries where most humanitarian crises occur, these figures are higher.[1] Armed conflicts and emergencies increase harm, raise barriers, and worsen multiple forms of discrimination, thus enhancing the risk of developing long-term impairments and secondary or aggravated health conditions (Lord, 2018).

Persons with disabilities commonly face severe obstacles in accessing crucial protection and other humanitarian services including health care, food aid, and water, sanitation and hygiene (Handicap International, 2015, 11). The deterioration or collapse of these services creates disability-specific barriers and risks, while communication strategies do not adequately reach persons with disabilities (Handicap International, 2015, 15). Mobility difficulties, loss of assistive devices (such as wheelchairs, canes, crutches, hearing aids, and prosthetics), inaccessible evacuation routes and transportation services, and abandonment by or loss of caregivers create additional barriers for persons with disabilities in attempts to escape danger (UNICEF, 2013, 49; UNICEF, 2018, 8). This results in higher mortality and morbidity rates. Even in a rich country like Japan, persons with disabilities were twice as likely to be killed or injured as those without disabilities during the 2011 earthquake and tsunami (OCHA, 2014).

In protracted crises, persons with disabilities have only limited access to livelihoods, employment, and educational opportunities, which increases the risk of living in poverty and becoming even more marginalized than before (UNICEF, 2018). Multiple and intersecting forms of discrimination also exacerbate the risks for persons with disabilities (UN CRPD/CSP/2017/3, 2017, 2). Women and girls with disabilities, for instance, are exposed to much higher risks of violence and sexual exploitation (UN

[1] One survey found that the disability prevalence among adults in Afghanistan was almost 79 percent (Asia Foundation 2019, 18). In Syria, estimates are that between 18 and 30 percent of the population has a disability (Skinner 2014, 39–40; UN Syria 2019).

General Assembly A/67/227, 2012, 4; Namatovu et al., 2018). About a third of women with disabilities experience psychological, sexual, or physical abuse (Handicap International, 2015, 9). Children with disabilities and their families and caregivers[2] are more likely than others to be poor and excluded from education and accessing targeted and general support services (UNICEF, 2013, 49). Sometimes, persons with disabilities are ostracized by their communities.

Humanitarian crises also generate increased numbers of people with impairments and chronic diseases due to injuries resulting from direct violence, landmines and other explosives, or owing to a loss of medical treatment, malnutrition, and access to immunization (UNICEF, 2018, 11). In the Syrian Arab Republic, for example, "a breakdown of services and lack of humanitarian access to certain parts of the country were linked to polio outbreaks […]" (Al-Moujahed et al., 2017).

Moreover, human rights violations on account of a disability, including forced sterilization, involuntary medical and scientific experimentation, human trafficking, forced disappearances, and attacks against buildings dedicated to the education, health care, and rehabilitation of persons with disabilities often remain unaddressed by fact-finding bodies and tribunals (Pons et al., 2022, 58–59).

The COVID-19 pandemic has aggravated the situation for persons with disabilities, with persons with intellectual disabilities having a disproportionately high risk of contracting the virus due to difficulties to ensure adequate physical and social distance to professionals and relatives, who provide daily support (Doody & Keenan, 2021, 799). Moreover, preventive measures during the height of the pandemic had a major impact on their lives, leading to increased experiences of distress, loneliness, and agitation (Embregts et al., 2022; Thalen et al., 2021). A survey found that in South Sudan, public health messages to limit the spread of the virus were not inclusive and accessible while inaccessible hand washing stations, latrines, and bathrooms put persons with disabilities at a higher risk of infection than persons without (Humanity & Inclusion, 2020, 5). Undoubtedly, environmental, attitudinal, and institutional barriers exacerbate the vulnerability of persons with disabilities, which leaves their

[2] Traditionally, the term caregiver has been used frequently, but due to its paternalistic and medical overtones, it is increasingly being replaced by support person or personal assistant. Here we stay close to the original source, which uses the term "caregiver" (UNICEF 2013).

basic needs and specific requirements unaddressed, while their agency, capacities, and resources are too rarely noticed.[3]

These examples of failures to protect persons with disabilities illustrate the low capacity of the humanitarian system and International Law to deal with human diversity and ensure that persons with disabilities can participate in their societies on an equal basis with others. These examples also contradict the four core humanitarian principles, according to which human suffering must be addressed wherever it is found (humanity), aid must be provided on the basis of need alone, giving priority to the most urgent cases of distress (impartiality), humanitarian actors must avoid taking sides in hostilities (neutrality), and humanitarian action must be autonomous from political, economic, military, or other objectives of other actors (independence) (OCHA, 2012).[4]

Nevertheless, recent years have witnessed a growing awareness of the failures in the application of these core principles, as well as serious gaps in the inclusion of persons with disabilities in humanitarian policy and response. Particularly since the launch of the *Charter on Inclusion of Persons with Disabilities in Humanitarian Action* (a.k.a. *Humanitarian Disability Charter*) at the 2016 World Humanitarian Summit, resolutions, non-binding agreements, and guidelines have emerged at the international level. These documents reflect a new human rights-based understanding of disability—in line with the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD)—and promote disability-inclusive humanitarian action. They elucidate and strengthen the normative basis for action and encourage humanitarian actors, including donor states, UN organizations, the Red Cross and Red Crescent Movement, and NGOs, to adapt their policies and increase their accountability toward persons with disabilities.

Despite these developments, there remains a question about the extent to which the human rights-based understanding of disability has gained a foothold in humanitarian policy and practice. In other words, has

[3] Persons with disabilities have the same basic needs in humanitarian emergencies as persons without disabilities but may also have specific requirements depending on their respective impairments. Yet, both have long remained unaddressed in humanitarian response activities (Handicap International 2015).

[4] These principles are also endorsed in UN General Assembly Resolutions 46/182 (1991) and 58/114 (2004).

disability inclusion established itself as a robust norm (cluster)[5] that regards persons with disabilities not as passive recipients of aid requiring treatment and care but as partners who can exercise their rights on an equal basis with others?

1.3 Purpose and Central Research Question

This book addresses the challenges of acknowledging and accommodating human diversity, particularly including persons with disabilities and the degree to which disability is being integrated in international law and humanitarian action.[6] The risks persons with disabilities face in humanitarian crises, and their rights, needs, and capacities still receive too little attention in humanitarian policy, practice, and research. Hence, this book asks:

> How does the disability inclusion norm cluster maintain, strengthen, or lose its robustness during processes of institutionalization, translation, and implementation?

The book adopts a multi-level Sociology of Law perspective (Lohne & Sandvik, 2017), going beyond state-level ratification, accession, or formal acceptance of a norm, treaty, or convention. This perspective allows for a broader, more dynamic understanding of norms at several levels of global governance and provides insights on how norms are interpreted, strengthened, or weakened by practices and interactions among the various state and non-state actors involved in humanitarian crises and how these norms in turn also influence the behavior of these actors. The following sub-questions will be addressed:

[5] A norm cluster consists of a set of related component norms, which each form a nexus between a problem, a value, and a behavior (Winston 2018, p. 641, see Chapter 2).

[6] Searle defines inclusion in humanitarian action as activities "taken to ensure the right to information, protection and assistance for all persons affected by crisis, irrespective of age, sexual and gender identity, disability status, nationality or ethnic, religious or social origin or identity. Inclusive action focuses on identifying and removing barriers so that those individuals and groups who are more vulnerable, marginalized and/or excluded can participate in decision-making and benefit from humanitarian action on an equal basis with others" (Searle et al., 2016).

1. Do norms really change the practices of the actors involved? And if so, how?
2. What is the impact of these norms on the lives of persons with disabilities?

To answer these questions, we develop a theoretical framework, which looks at (1) the structure of the disability inclusion norm (cluster), (2) its addressees and targets; and (3) the levels of global governance to which it applies. We show that the robustness of norms does not reveal itself in the ratification, accession, or official acceptance, but rather in their translation into policy and implementation on the ground. Thus, we argue that it is necessary for International Law and International Relations (IR) scholarship to pay more attention to processes "below" the international level. In doing so, we challenge traditional International Law and IR perspectives, which devote most attention to norm development, norm change, and norm contestation among states at the international level and give only little attention to translation and implementation. These perspectives result in an inability to explain the actual impact of the component norms of a norm cluster on policies and practice at different levels of governance. In this way, we show the challenging move from changing norms to changing practice, which is central to promoting disability inclusion and understanding diversity. International Law and IR need to take the "lived realities" of disability inclusion into account.

1.4 Overview of the Book

This book is divided into seven chapters: After this introduction, Chapter 2 develops a theoretical framework and discusses research methods for studying disability inclusion at different levels of global governance based on different strands of IR norm theory. We discuss norm clusters in IR scholarship and explain the "disability inclusion"

norm cluster.[7] In the process, we assess the utility of the norm cluster approach for studying international norms.

Chapter 3 examines how activists, organizations of persons with disabilities[8] (OPDs), and international organizations established disability as a human rights issue, which differs from traditional views on disability, specifically the charity and medical models. The chapter discusses the central relevance of the CRPD for humanitarian policy and practice. It shows how the CRPD marks a shift from disability as a deficit to disability that arises "when individuals with impairments interact with the barriers they face", which has crucial implications for how humanitarian and other actors should address disability (IASC, 2019, 6).

Chapter 4 studies how the main international actors in the humanitarian system—donors, intergovernmental bodies, and humanitarian organizations—have translated disability inclusion into their policies. The first part investigates the policies of the main humanitarian donors. It shows that despite growing attention, donor governments vary considerably in their approaches to disability inclusion and must improve their translation further. The second part comparatively describes and analyzes the donor approaches. It reveals that most donor approaches are too abstract and general for implementation. The third part studies translation at the interorganizational level. It explores how humanitarian organizations (1) promote meaningful participation of persons with disabilities; (2) address barriers; (3) exercise data collection and monitoring; and (4) engage in empowerment and capacity building. This part reveals that these organizations gradually adapt their practices and struggle with considering the diversity of the populations they seek to support. The fourth part of this chapter comparatively describes the measures that organizations have taken so far to translate disability inclusion. The last part

[7] Importantly, the norm cluster is an analytical concept that must not be confused with the actual cluster coordination system in humanitarian action. The coordination clusters are groupings of humanitarian organizations, which operate in specific technical sectors, such as nutrition, health, or protection, and coordinate action, promote common strategies and good practices to avoid duplication, address gaps, and share information (Global Education Cluster et al., 2020).

[8] OPDs are organizations predominantly run by persons with disabilities (in contrast to welfare and rehabilitation organizations and inclusion-focused NGOs that largely consist of non-disabled "experts") and have the intention to represent their interests, raise awareness, and advocate for their rights (IASC 2019a, 33).

analyzes norm translation by donor governments and at the humanitarian interorganizational and organizational levels.

Chapter 5 comparatively examines the implementation of disability inclusion in two different humanitarian crises. We look at domestic government policies and humanitarian action in the Rohingya refugee crisis in Cox's Bazar, Bangladesh, and the humanitarian crisis in war-torn South Sudan. It becomes clear that many organizations know about the CRPD and recognize the need to become disability-inclusive. However, most struggle with the implementation of the disability inclusion norm cluster. This chapter elucidates the reasons for incomplete implementation and limited impact.

Chapter 6 analyzes the key findings using the theoretical framework developed in Chapter 3. We highlight important differences among the levels of global governance and show the shortcomings of norm robustness as a concept for the study of norm translation and implementation. We also present recommendations to strengthen inclusion of persons with disabilities in humanitarian policy and practice at the various levels of global governance.

The concluding chapter summarizes the findings, discusses the shortcomings of current IR norm theory, and highlights the need for a multi-level perspective for studying norm robustness. It is impossible to understand the politics and governance of human diversity without thoroughly reflecting on how global norms are translated into policy and implemented into practice. Whereas studying norm institutionalization at the international level requires concepts such as norm contestation regarding the meaning of norms, norm evasion is a more useful term to understand the limited effect of norms during translation into policies and implementation on the ground. We also suggest further research themes to study the evolution of varied (human rights) norm clusters at multiple levels of global governance.

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CHAPTER 2

Understanding Norms, Norm Clusters and Robustness at Different Levels of Global Governance

Abstract This chapter develops a theoretical framework and methods for studying disability inclusion at different levels of global governance based on different strands of IR norm theory. It also discusses the methods of data collection and analysis for each level of global governance and develops a multi-level perspective that goes beyond traditional International Law and IR approaches to understand the (limited) impact of disability inclusion in humanitarian crises so far.

Keywords IR norm theory · Mixed methods · Norm cluster · Norm robustness · Impact · Levels of analysis

2.1 Introduction

A plethora of legally binding and non-legally binding norms governs the humanitarian system. These norms derive from legal standards, international principles and guidelines, which officially enjoy strong support

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from donor governments and humanitarian organizations.[1] Most international norms and standards require humanitarian actors to consider the needs and specific requirements of persons with disabilities in the event of an emergency, yet without articulating the parameters of their protection (Lord, 2018). In other words, they do so implicitly as part of a general protection norm to which all civilians are entitled in humanitarian crises. To begin to understand norms, this chapter first gives a short overview of norm research and theories and then discusses the methodological approach to study norm development at different levels of global governance.

2.2 A Brief History of Norms in International Relations

In the early twentieth century, International Relations slowly became institutionalized as a field of study. Many of the first generation of IR scholars had a background in International Law. Most of their studies were of an applied, legal, or historical nature (Dijkzeul & Salomons, 2021, 6). Together with International Law scholars, they held that norms played a crucial role in world politics. Changing them would be one of the main ways to improve the world and ensure peace. In addition, many scholars of both fields hoped that international organizations would be the main tool to convince states and other actors of these norms. In the 1930s, some scholars started to protest these idealist assumptions. They argued that power, especially state power, explained more of IR. The use of power as an explanatory concept helped set IR apart from legal studies (Dijkzeul & Beigbeder, 2003). Over the years, attention to norms has waxed and waned in IR, whereas it has continued in International Law (Bogdandy & Venzke, 2013; Fomerand, 2017; Noortmann, 2019; Waal, 2003).

Currently, the three main IR schools hold distinctive positions on norms. Ideal-typically, IR *realists* assume that norms barely matter in world politics. For them, state power, especially in military and economic

[1] International humanitarian law (IHL), international human rights law, human rights, refugee law, international criminal law, the Code of Conduct for the International Red Cross and Red Crescent Movement and NGOs in Disaster Relief, the humanitarian principles, as well as non-binding rules and regulations on internal displacement from the Guiding Principles on Internal Displacement.

relationships, explains most international affairs. Norms are a peripheral phenomenon. Reacting against realism, *constructivists* tend to overstate the influence of actor identities, ideas, and norms to the exclusion of material and institutional factors; and *liberals* over-rely for explanation and policy on the diffusion of universal international norms and institutions that guarantee their own implementation and effectiveness (DeMars & Dijkzeul, 2025). However, if norms were truly universal, they would endure over time, be uniform across places, take political precedence over other interests and commitments, and have the causative power to guarantee reliable and effective results (DeMars & Dijkzeul, 2025). Although some IR scholars argue that either raw power without norms or universal norms help with devising parsimonious explanations, most IR scholars reason less ideal-typically. They take up a position in between the extremes that norms either can be fully universal or barely matter.

In such IR scholarship, Katzenstein's definition of norms as "shared expectations about appropriate behavior held by a collective of actors" (Katzenstein, 1996, 5) has become a common standard. IR scholars describe four central features of norms: intersubjective agreement on their contents, immediate behavioral orientation, counterfactual validity, and inherent value (Boekle et al., 1999; Finnemore & Sikkink, 1998; Florini, 1996). The intersubjective nature of norms—shared expectations—does not qualify them as universal and objective, but as valid within a certain community or collective, where the norms are shared. The immediate behavioral orientation means that norms guide or motivate behavior or at least make an appeal to do so. The counterfactual validity of norms means that norm violations do not necessarily cause a norm to lose its validity (Boekle et al., 1999, 6). This counterfactual validity is crucial in international humanitarian law given its many violations. Finally, norms have inherent value, which strengthens the willingness of stakeholders to follow them. The last three features all show the deontological character of norms. Nonetheless, what can be considered appropriate or inappropriate behavior and what constitutes a collective remain particularly vague (van Kersbergen & Verbeek, 2007), which has led to theoretical debates on contestation, continuity, and change in the process of norm adoption and evolution (Winston, 2018). Which collective(s) of actors are to be included? And which people are left behind? Moreover, who determines what is appropriate or inappropriate in a community? In sum, how

strong can or should the intersubjective deontological norm features be to influence the practices of various actors?

In addition, most IR scholars acknowledge that international norms also play out at the national level. They mention, for example, international negotiations about norms and policies as a two-level game (Putnam, 1988). However, as stated, they rarely go beyond treaty ratification to look at national or local politics. In other words, they have a too narrow and homogeneous definition of the actors constituting and influencing the international community.

We hold that the three main IR schools need to upgrade their ideas of norms and levels. Otherwise, IR will fail to do justice to the manifold—positive and negative, as well as imperfect or incomplete—ways that norms influence practice, not just of states but also of other actors in the IR zoo. To do so, we now turn toward two more specific norm theories: norm cluster and norm robustness theory.

2.3 Norm Clusters in Theory

To remedy the problem of what is appropriate or inappropriate, Winston suggests taking a close look at the structure of norms themselves. She sees a norm as a nexus between a problem, a value, and a behavior (Winston, 2018, 641). The value is subjective but important as it identifies the problem and limits the behavior that is appropriate to solve it (Winston, 2018, 640). She argues that norms often appear as a cluster, defined as "an expanded space within multiple combinations of problems, ideations, and behaviors" that result in an intersubjective (i.e., collectively held) acceptable set of solutions (Winston, 2018, 654).

Applied to disability inclusion, the norm cluster consists of a clearly defined problem, namely the neglect of persons with disabilities in humanitarian crises, the value, based on Article 11 of the CRPD that their inclusion must become an integral part of humanitarian action, and a set of different expected behaviors. These behaviors derive from the CRPD, in particular its general principles (Article 3) and general obligations (Article 4). They include the principles of non-discrimination, full and effective participation, equality of opportunity, and accessibility, and the obligation to ensure and promote the full realization of all human rights and fundamental freedoms. In addition, the specific Articles of the CRPD provide necessary aspects of complying with those general

principles in particular areas, such as education and health. These principles and general obligations informed the 2019 Inter-Agency Standing Committee (IASC) *Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action*, in short, the *IASC Guidelines* (see sections below).[2]

Winston's definition differs from Lantis and Wunderlich who regard clusters as "collections of aligned, but distinct, norms or principles that relate to a common, overarching issue area" (Lantis & Wunderlich, 2018, 571). In the latter's understanding, the specific obligations of the specific norms in the cluster "usually, but not necessarily, coincide" (Lantis & Wunderlich, 2018, 571). Whereas Winston (2018) and Lantis and Wunderlich (2018) simply use the concept norm, we differentiate between a norm cluster and its parts that we call "component norms". Lantis and Wunderlich give the example of the non-proliferation regime complex, which consists of three major (component) norms: First, the obligation of nuclear-weapon states not to transfer nuclear technologies to non-nuclear-weapon states. Second, the right to access the peaceful uses of nuclear energy. Third, the obligation to work toward nuclear disarmament. "These norms are effectively bound by a central logic of restraint" (Lantis & Wunderlich, 2018, 583).

This conceptualization of norm clusters is more difficult to apply to human rights norms. Particularly the CRPD, which contextualizes disability within the broad human rights lexicon, initiates a dynamic treaty practice that interacts with and advances interpretations of other international law domains, such as refugee and asylum law (Lord et al., 2022) and international criminal law (Pons et al., 2022). Furthermore, international Conventions like the CRPD usually do not discriminate between classes of states but apply equally to all States Parties.[3] Moreover, they are not only bound to a central logic of restraint, but also by a 'logic of action', in the case of the CRPD to protect the rights of persons

[2] The IASC is the high-level humanitarian coordination body of the United Nations System, International Committee of the Red Cross, International Federation of Red Cross and Red Crescent Societies, and international NGO umbrella organizations. The UN Office for the Coordination of Humanitarian Affairs (OCHA) functions as its secretariat. For more information, see https://interagencystandingcommittee.org/.

[3] However, in the case of socio-economic rights states are bound to invest the maximum amount of resources, pass legislation, and adopt and execute concomitant policies. This obligation applies to the resources existing within a state and those available from the international community.

with disabilities. This logic of action then requires multiple actions simultaneously. However, in practice these multiple actions may need to be prioritized during operationalization.[4] Four component norms play a crucial role in this logic of action, as they connect problems, values, and behavior more specifically than the overarching disability inclusion norm. These component norms correspond to the four "must-do" actions for disability inclusion outlined in the *IASC Guidelines*: (1) promote meaningful participation; (2) remove barriers; (3) empower persons with disabilities and support their capacity development; and (4) disaggregate data for monitoring inclusion (see Chapter 4).

2.4 Norm Robustness in Theory

A second strand of norm theory discusses the robustness of norms. Human rights "norms are considered to be robust when they are regarded as legitimate, endorsed, ratified, and followed by a critical mass of players" (Lantis & Wunderlich, 2018, 574). This implies that "they are regularly cited in international discourse, included in policy statements … and implemented into national law and regulations" (Lantis & Wunderlich, 2018, 574). According to Deitelhoff and Zimmermann (2019, 3), the robustness of a norm is high "when its claims are widely accepted by norm addressees (validity) and generally guide the actions of these addressees (facticity)". Conversely, robustness is low "if there is limited international acceptance and support or compliance" (Lantis & Wunderlich, 2018, 574). Nevertheless, these authors leave out the evolution of norms "below" the national policy level. They also do not determine what precisely constitutes a critical mass, and how to measure wide norm acceptance empirically across levels of global governance. Importantly, like most IR and legal scholars, they consider norm addressees predominantly to be states in the international system. Hence, the problems of defining appropriate behavior and determining who constitute the collective come back under a different name. This is especially a problem for studying inclusion, because including diversity often implies broadening the "collective" with the excluded or discriminated groups.

[4] Note how the distinction between a logic of restraint and the logic of action correlates with the distinct roles of national governments with respectively negative and positive rights.

We argue that in order to understand progress and gaps in inclusion, we need a broader conceptualization of the term "norm addressees" than states. It should also include those actors who 'make a norm come to life' on the ground.

For the study of norm robustness at different levels of global governance, it is thus crucial to distinguish between states, humanitarian organizations, OPDs, and others who express formal commitment to these human rights norms, for example in their internal policies but are not formally bound to them in International Law. According to this understanding, norm addressees may also be organizations or groups in society that cannot officially endorse a norm through established inter-state mechanisms of norm acceptance (ratification, accession, subscription).

In sum, merely looking at the numbers of CRPD ratification offers only a limited picture of the inclusion norm's robustness and the extent to which the human rights-based understanding of disability inclusion has gained a foothold in the humanitarian system for three reasons. First, the CRPD is only open to States Parties and regional organizations and does not give other actors in the humanitarian arena the chance to endorse its norms in a similar manner—although some OPDs and civil society actors leverage ratification by states to advance inclusion through legal pressure and advocacy. Second, and more importantly, treaty ratification says little about how States Parties and other actors interpret the norms and how these guide their actions. "Just because two states have signed and ratified the same international norms, or similarly incorporated them within domestic law, does not necessarily mean that they will be similarly implemented" (Betts & Orchard, 2014, 1). Third, whereas some OPDs and other civil society actors will reference the CRPD as a guide, other actors may neglect or reject the CRPD. In the end, norm robustness is not only determined by the acceptance and behavior of states, but depends on norm enactment by a larger, and more diverse range of actors at different levels of global governance.

2.5 Levels, Organizations, and Policy Mechanisms

Betts and Orchard (2014) redefined and specified the terms "institutionalization" and "implementation" in an elaboration of the well-known norm life cycle of Finnemore and Sikkink (Finnemore & Sikkink, 1998, 896). For them, institutionalization refers to the process by which norms

emerge and become reflected in international law and organizations, and implementation describes the steps that are necessary to introduce the norm into legal and policy mechanisms (Betts & Orchard, 2014, 2). These processes may influence and interact with each other (Betts & Orchard, 2014, 5). Betts and Orchard focus merely on the national level, but implementation also occurs "in the field", for example, when organizations apply these norms in their programs and daily operations. To make a more precise conceptual distinction, Zimmermann (2016) therefore speaks of norm "translation" when referring to the process by which states and other actors incorporate global norms into national laws and/or organizational policies and of "implementation" to refer to the local dimension of a norm's practical application. To determine the robustness of a norm or a norm cluster, it is useful to combine the approaches by Betts and Orchard with Zimmermann's into a multi-level approach. We therefore conceptually distinguish between three different, but related processes of norm development, namely *norm institutionalization*, *translation*, and *implementation* that take place at different societal levels, which fits well with a Sociology of Law perspective.

Norm institutionalization describes the process of achieving official acceptance of a norm through treaty signature, ratification, or accession. It occurs at the international level and mainly but not only involves states. It is the standard face of International Law and IR. *Norm translation* takes place when national governments or organizations actors embed international norms in their respective policies. And *implementation* is concerned with the necessary actions to reach the norm 'targets' "on the ground"(Betts & Orchard, 2014, 5). Translation and especially implementation involve a wide range of actors beyond states (Table 2.1).

The ways in which the different levels are constituted and influence each other is first and foremost an empirical question. At times, the actions at one level may not influence another much. Rhetoric may sound good, but not leave an impact, and substantive reports may gather dust on bookshelves. At other times, all levels may be deeply influenced by each other, although the exact magnitude may not be clear at first sight. In these cases, it is not always easy to make sharp distinctions between institutionalization, translation, and implementation because these processes then interact with and inform one another (Funke, 2022). But even when the actors and mechanisms from different levels intensely influence each other, they cannot be reduced to each other, because the types of actors and mechanisms vary and cause different, albeit sometimes overlapping

Table 2.1 Levels, mechanisms, actors, and outcomes

Levels of global governance	*Main mechanism of norm development*	*Main actors/Norm addressees*	*Desired outcomes*
International Level	Institutionalization	States in intergovernmental organizations (e.g., UN System) and coordinating bodies	Resolutions, treaties, conventions, international standards, guidelines
National Level and Interorganizational (Strategic) Level	Translation	National governments, strategic management of humanitarian organizations	Domestic law and/or thematic policies
Local Level	Implementation	Humanitarian organizations at country/field level, target groups, and other actors in the humanitarian arena	Access to assistance and protection for people of concern / target groups

outcomes for each level. Scholars that focus on one level either implicitly assume that action at one level smoothly influences the other levels or that other levels are simply not relevant. In both cases, the scientific understanding of norm development and impact of these disciplines is severely curtailed. This has happened too often in both International Law and IR.

Above we described the problems with determining the "collective" or "community" that shares a norm. Distinguishing these levels partly addresses this problem, because it is often easier to distinguish the relevant, varying actors for each level than comprehending all of them at once.

From a multi-level perspective, the inclusion of persons with disabilities is not just about whether a norm should exist or not, but also about whether the adoption of the CRPD in 2006 and its translation and implementation have strengthened a human rights-based understanding of disability inclusion by which donors and humanitarian actors ensure that persons with disabilities have access to protection and assistance on an equal basis with others (Searle et al., 2016, 7).

This implies that it is fruitful to explore how a rights-based understanding of disability inclusion in humanitarian action has evolved.

Otherwise, understanding diversity and promoting inclusion will remain superficial. After all, inclusion also entails shifting the power balance among actors and its study also requires examining national and subnational levels (Búzás, 2022; Crowley-Vigneau, 2022), as well as the interaction of actor collectives—donor governments, UN bodies, international NGOs, OPDs, persons with disabilities, and so on—across these levels. Ultimately, it is the changes in the lives of persons with disabilities that show the impact of the norm cluster.

In the empirical chapters, we first examine the international level. In a second step, we study how prominent donor governments in the humanitarian arena conceptualize and translate disability inclusion in their policies and activities. Next, we look at the translation of disability inclusion at the strategic level of humanitarian organizations, and then implementation in two crises—in Cox's Bazar, Bangladesh and South Sudan—to better understand how norms shape and are shaped by practices and interactions of various actors at different levels of global governance.

2.6 Methods and Case Selection

Studying norms at different levels of global governance requires a *qualitative mixed methods* approach. For *institutionalization* at the international level, we use legal and policy analysis, and collect data from international databases and websites in Chapter 3. We additionally analyze UN resolutions and policy documents, international conventions, and declarations.

For *translation* into domestic policy at the national level, we collect, analyze, and compare national policies and financial data of the main donor governments in Chapter 4 to better understand to which extent they have incorporated the four component norms into policy. We also study *translation* at the policy level of international organizations by collecting and analyzing their policies, strategic frameworks, policy evaluations, and official websites.

By comparing two dissimilar case studies on disability inclusion in two humanitarian crises, Cox's Bazar, Bangladesh and South Sudan, we analyze *implementation* at the ground level in Chapter 5.[5] The two states differ in their degree of statehood: the Bangladeshi government

[5] Research in Bangladesh took place in 4 weeks in January and February 2020 and in South Sudan over 10 weeks between June and August 2021 (see Funke & Dijkzeul,

is stronger than the South Sudanese one and has the authoritarian power to control the humanitarian work of international and national organizations.[6] Whereas in Bangladesh, humanitarian action is limited to the Cox's Bazar district, where almost one million Rohingya have sought shelter after mass atrocities in Myanmar, in South Sudan, two-thirds of the population across the country depend on humanitarian assistance. Yet, both countries experience a protracted crisis, receive huge amounts of funding, and host a large variety of humanitarian organizations. This allowed us to broaden our analysis of inclusion to different types of actors.

For analyzing implementation, we rely on 49 semi-structured expert interviews with humanitarian practitioners from 32 different organizations. In Bangladesh, 34 individuals from 18 different organizations participated in this research. One interview was conducted remotely with a representative from the national authorities (Funke & Dijkzeul, 2021b). In South Sudan, 15 experts from 14 organizations were interviewed remotely via Zoom or Skype.[7] Requests to interview a representative from the national authorities remained unanswered (Funke & Dijkzeul, 2021a).

In addition to interviews, research consisted of one focus group discussion with eight field staff from an international mainstream humanitarian NGO working on protection in the refugee camps and host communities in Teknaf and Ukhiya in Cox's Bazar, and two focus group discussions with 21 representatives from OPDs in South Sudan (five women and five men in Yei; four women and seven men in Yambio). Moreover, it included a review of gray literature from Humanity & Inclusion (HI), Christian

2021a: 28, 2021b: 16). Data analysis took place intermittently over a year after the field visits and was reviewed again for this publication.

[6] During the field research in 2021 in Bangladesh, there was criticism and occasionally protests against the government of Bangladesh, but its authoritarian measures against its own population as well as the refugees in Cox's Bazar still looked strong. Only in 2024, just before this book going into print, did protests against authoritarian rule, especially in the capital, Dhaka, succeed in removing the authoritarian government. It is too early to tell what this change will mean for the Rohingyas in Bangladesh.

[7] Originally, we had planned the same design for field research in South Sudan. Due to COVID-19, however, a field visit was not possible. "This limited the number of interview partners significantly since interviews could not be arranged spontaneously 'on the spot'. Moreover, the researchers were unable to participate in relevant meetings, visit intervention sites and learn from observations and informal conversations with humanitarian staff" (Funke & Dijkzeul, 2021a: 18). COVID-19 also hindered access to national authorities in South Sudan.

Blind Mission (CBM), and their local partner organizations. This included barriers and facilitators assessments, project proposals and project information sheets. In Bangladesh, one author also participated in cluster and staff meetings in Cox's Bazar, visited refugee camps and engaged in informal exchange with international and national humanitarian staff involved in the Rohingya refugee response.

All interviews were transcribed and analyzed with MAXQDA software. Coding was based deductively on the four "must-do" actions from the *IASC Guidelines* and inductively on themes, such as "collaboration and cooperation" and "challenges in daily work", that came up during the interviews (Funke & Dijkzeul, 2021a: 30–31, 2021b: 18–19). Staff from HI, CBM, and their partner organizations also provided substantial feedback on drafts of the two research reports (Funke & Dijkzeul, 2021a, 2021b) and this book.

The following three chapters will examine norm *institutionalization*, *translation*, and *implementation* empirically to explain the impact and robustness of the disability inclusion norm cluster.

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CHAPTER 3

Institutionalizing a New Understanding of Disability in Humanitarian Action at the International Level

Abstract This chapter examines the traditional views on disability (e.g., the charity and medical models), how activists, organizations of persons with disability (OPDs), and international organizations made disability a human rights issue, and discusses the central relevance of the CRPD for humanitarian policy and practice. In short, this chapter discusses how and to which extent a human rights model of disability has been institutionalized at the international level.

Keywords Models of disability · CRPD · Norm institutionalization · Disability rights movement · United Nations

3.1 Introduction

In the first two and a half decades of the United Nations, persons with disabilities were "more or less invisible" as citizens and human rights holders (Degener & Begg, 2017, 3). Instead, a paternalistic and medical-centric approach prevailed that reduced disability to an impairment. Starting in the late 1960s, disability organizations and advocates have lobbied intensively for a move away from the perception of disability as a medical observation and physical limitation (Bantekas & Oette, 2020, 591). With the adoption of the CRPD in 2006, a human rights model

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established itself that demands respect for dignity, full and effective participation and inclusion in society as well as equality of opportunity. This chapter discusses how a human rights-based understanding of disability has been institutionalized at the international level and examines its relevance for humanitarian action.

3.2 Background to the Formation of the CRPD

For a long time, support for persons with disabilities was rooted in the *charity model*, which predominantly sees them as victims or dependents unable to care for themselves. Rather similarly, the *medical model* reduces disability to a medical phenomenon of impairment, "that needs to be treated, cured, fixed or at least rehabilitated" (Stein & Lord, 2009, 20). The medicalized approach to disability is also reflected in the terminology of international humanitarian law, in which persons with disabilities are variously referred to as the "infirm", "wounded", "sick", and "disabled". Other terms, which refer to certain categories of individuals with disabilities, as persons with "mental disease" or individuals who are "blind", "maimed", or "disfigured" also fit the charity and medical model (OHCHR, 2015, A/HRC/31/30; Lord, 2018). When the UN General Assembly began to engage with the rights of persons with disabilities in the early 1970s, its non-binding declarations also reflected features of the charity and medical models.[1]

With the emergence of the disability rights movement in the late 1960s, persons with disabilities and their representative organizations increasingly challenged these two models that locate disability with the individual and their impairment. They promoted new models. The most prominent one, the *social model*, regarded disability as a social construct, according to which exclusion from society is no longer a product of impairments but a result of a disabling environment, barriers, and cultures

[1] For example, UN General Assembly Res. 2856 (XXVI), 1971; UN General Assembly Res. 3347 (XXX), 1975. Art. 1 of the Declaration on the Rights of Mentally Retarded Persons reads: "The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings". Article 3 of the Declaration on Disabled Persons spells out: "Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age". Furthermore, Art. 4 stresses: "Disabled persons have the same civil and political rights as other human beings".

(Barnes, 2012, 18). Several UN General Assembly resolutions endorsed this understanding of disability. The 1982 *World Programme of Action Concerning Disabled Persons* (Quinn et al., 2002, 30), for example, embraced the social model and promotes disability prevention, rehabilitation, and the equalization of opportunities (UN General Assembly Res. 48/96, 1994; Quinn et al., 2002, 31; van Weele, 2012). The 1993 *Standard Rules on Equalization of Opportunities for Persons with Disabilities* (UN General Assembly Res. 48/96, 1994, 22) underscored the right to equal participation of persons with disabilities and established "a monitoring mechanism through the appointment of a Special Rapporteur who reports to the Commission for Social Development" (Stein & Lord, 2009).[2] The *Standard Rules* were also significant because their language began to resemble a rights-based approach. Nevertheless, they failed to assert that persons with disabilities are full citizens and rights holders (Begg, 2022, 137).

After the turn of the century, organizations of persons with disabilities, including Disabled People's International, Inclusion International, Rehabilitation International, the World Blind Union, and the World Federation of the Deaf, began to lobby hard for a legally binding convention (Quinn et al., 2002, 293). In 2001, with support from the Mexican delegation, the General Assembly passed a resolution that created the so-called Ad Hoc Committee of the CRPD to examine proposals for a convention (Degener & Begg, 2017, 13,15). In August 2006, the Ad Hoc Committee approved a draft text of the Convention and its Optional Protocol. In the same year, and after some minor revisions, the General Assembly adopted the Convention and its Optional Protocol by consensus (UN Department of Economic and Social Affairs – Disability, n.d.a). They entered into force on 3 May 2008 after the deposit of the twentieth instrument of ratification or accession (Article 45).

Officially, the CRPD enjoys strong support from states. As of September 2024, there were 191 States Parties and 164 signatories to the Convention (UN Treaty Collection, n.d.b). Its Optional Protocol,

[2] Bengt Lindqvist, a blind former minister of Sweden (1992–2002), Sheika Hessa Al Thani of Qatar (2003–2005), and Shuaib Chalklen (2005–2014), a wheelchair user from South Africa, successively held the position until its replacement in 2014 with a new position of special rapporteur on the rights of persons with disabilities. In 2020, lawyer Gerard Quinn replaced the previous mandate holder, Catalina Devandas Aguilar (UN Department of Economic and Social Affairs – Disability, n.d.b).

which establishes procedures for individual and group complaints on violations of the CRPD, has been signed by 94 states and ratified by 106 (UN Treaty Collection, n.d.a). The advocacy for a new human rights convention was so successful because many states, activists, and international organizations supported the issue content—demanding equality and non-discrimination (Price & Sikkink, 2021, 40).

Such almost universal endorsement can be explained by the fact that disability inclusion is connected to powerful moral foundations—inherent dignity, non-discrimination, full and effective participation in society, respect for differences and acceptance of persons with disabilities as part of human diversity, equality of opportunity, accessibility, and equality—that resonate with moral intuitions of both liberals and conservatives (Price & Sikkink, 2021, 40). Unlike other human rights norms, for example, concerning lesbian, gay, bisexual, transgender, queer/questioning, and intersex (LGBTQI+) individuals, the CRPD does not come into direct conflict with other moral institutions.[3] In short, there is *little open norm contestation* of disability inclusion at the international level of governance. From a traditional International Law and IR perspective, this suggests that the CRPD is a robust normative instrument. However, attention to translation and implementation (see below) shows that the ratification or accession to the treaty does not automatically translate into a 'robust' norm cluster.

3.3 The Convention on the Rights of Persons with Disabilities

The Convention itself was not intended to create new rights for persons with disabilities.[4] Instead, it builds upon and complements pre-existing human rights conventions, including the International Covenant on

[3] Price and Sikkink (2021, 4) explain that "campaigns for LGBTQ rights come into direct conflict with other powerful intuitions of 'sanctity/purity' around the world that have long demonized homosexuality as deviant and impure, as well as the moral foundation of obedience to authority, in this case religious authority". This is not the case with persons with disabilities.

[4] A similar process took place with the development of the Guiding Principles on Internal Displacement. Fearing that opening a discussion on a convention on internally displaced persons could actually weaken already existing norms on refugees and asylum seekers, the drafters of these Guiding Principles explicitly built on already existing conventions and resolutions (Funke & Dijkzeul, 2017). Hence, the formulation of both the

Economic, Social and Cultural Rights; the International Covenant on Civil and Political Rights; the International Convention on the Elimination of All Forms of Racial Discrimination; the Convention on the Elimination of All Forms of Discrimination against Women; the Convention against Torture and Other Cruel, Inhuman and Degrading Treatment of Punishment; the Convention on the Rights of the Child; the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families.[5] The rationale behind the development of a separate human rights treaty lies in the acknowledgment that pre-existing conventions did not sufficiently elevate the rights of persons with disabilities as equal rights holders (UN, 2008). Indeed, none of the abovementioned human rights treaties "expressly protected the rights of persons with disabilities" (van Weele, 2012, 10). Only the Convention on the Rights of the Child contains a distinct disability-related article, which gives children with disabilities the right to special treatment, education, and care (Stein & Lord, 2009, 20):

> States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child (Art. 23 (2)).

Crucially, the CRPD codifies a new human rights model of disability.[6] Persons with disabilities are no longer "viewed as 'objects' of charity, medical treatment and social protection but as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society" (UN Department of Economic and Social Affairs - Disability, n.d.a).

CRPD and the Guiding Principles on Internal Displacement built on existing international law in order to avoid norm contestation and potential weakening of norms.

[5] Its Preamble explicitly grounds the CRPD in these human rights treaties.

[6] In principle, persons with disabilities have the same rights and guarantees under existing human rights law. The CRPD differs in that it explicitly recognizes and elevates those rights, and emphasizes that an impairment does not diminish human dignity and equality. Moreover, it clarifies how existing rights should be applied to persons with disabilities.

The CRPD does not provide a universal definition of the term 'disability'.[7] The questions of including definitions of 'disability' and 'persons with disabilities' in the Convention "were among the most controversial" during the preparations (Cera, 2017, 84). Advocates of a definition wanted "to ensure that the Convention applied to all persons with disabilities" (Cera, 2017, 84). Opponents, in contrast, feared that a too open definition would have required them to recognize "a large number of impairment groups not traditionally understood as persons with disabilities within their societies" (Cera, 2017). Even the International Disability Caucus (IDC), a loose network of global, regional, and national organizations of persons with disabilities and allied NGOs participating in the negotiation process (2001–2006), objected to a definition of disability. On the one hand, IDC feared that a definition "would inevitably reflect the medical model and would be externally imposed and disempowering" (Cera, 2017). On the other hand, it argued "that the understanding of 'disability' as a social category is evolving over time and varying between societies" (Cera, 2017). Furthermore, an inclusion "of a definition in the CRPD runs the risk of imposing a western view of disability on non-western cultural systems" (Cera, 2017, 84–85). Eventually, an agreement was reached. Instead of introducing a clear-cut definition, Article 1 identifies the holders of all human rights set out in the CRPD: "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

In this way, the CRPD *conceptualizes* disability as an interactive and evolving concept (Washington Group on Disability Statistics, 2017, 15). It indicates that disability should be understood as a complex and dynamic process that "allows adjustments over time and in different sociocultural contexts" (Della Fina, 2017a, 97). Human diversity cannot be cast in stone and is regularly redefined by the recognition of differences and diverse groups over time.

The human rights model of disability differs from the social model in six ways (Degener, 2016, 3–14): First, whereas the social model only explains disability, the human rights model contains moral principles and

[7] This is a further illustration of the attempt to avoid norm contestation in order to prevent (potential) norm weakening (see UN Treaty Collection, n.d.b).

values that promote respect for the human dignity of persons with disabilities. Second, the human rights model moves beyond anti-discrimination policy and civil rights reforms and encompasses human rights and civil and political as well as economic, social, and cultural rights. Third, the human rights model does not neglect the experience of impairment and acknowledges specific living conditions, including pain, deterioration of quality of life, and early death due to impairment, but also "values impairment as part of the human diversity and human dignity" (Degener, 2016, 8). Fourth, the model values and acknowledges different layers of identity, such as gender, race, sexuality, and social background. The CRPD thus recognizes the issue of intersectionality; for example, both children and women with disabilities have stand-alone articles. Fifth, the human rights model acknowledges the need for prevention services and makes clear that the prevention of an impairment can be an important aspect of the right to health. Finally, it offers a roadmap to reduce the risk of poverty and offers a human rights approach to development that sees people in poverty as rights holders. In sum, the human rights model proactively acknowledges human diversity and promotes inclusion.

3.4 The CRPD and Humanitarian Action

The main purpose of the CRPD is to provide clarity to states about the legal obligations "to promote, protect and ensure the rights and fundamental freedoms of persons with disabilities" (Preamble CRPD). Article 3 therefore lays down eight general principles, which are affirmed in other human rights instruments as well as previous international texts related to the persons with disabilities, notably the 1993 UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Della Fina, 2017b, 121). These principles provide guidance to States Parties and stakeholders "to interpret the Convention's substantive rights and obligations" and "to achieve the purpose of the CRPD" (Della Fina, 2017b, 120), namely:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;

- Equality between men and women;
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Crucially for humanitarian action, the CRPD contains a separate article on the protection of persons with disabilities in situations at risk and humanitarian emergencies. This is one of the rare occasions where the CRPD differs from general human rights law (Article 11):

> States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

The article refers to two international law regimes, IHL and international human rights law, but the wording "including" makes clear that these are not the only regimes that apply in situations of risk and humanitarian emergencies. Refugee law, for example, is also relevant (Motz, 2018, 320). These legal regimes have to be applied simultaneously in crises. Moreover, unlike IHL, the article extends States Parties' obligations from situations of armed conflict to other situations of risk (Motz, 2018, 320). Another innovative aspect of Article 11 is that it "calls for international humanitarian law to be read through a human-rights based approach to disability" (OHCHR A/HRC/31/30, 2015, 3). This, as outlined by the UN High Commissioner for Human Rights (OHCHR) in 2015, "will necessarily lead to substantive changes in policy and practice of (donor) governments" (OHCHR A/HRC/31/30, 2015, 3). However, the exact extent to which these changes have occurred and whether the critical mass and wide acceptance exist has never been assessed before.

Initially, the adoption of the CRPD in 2006 did not have a tangible effect on humanitarian action. A 2015 global survey by Handicap International revealed that only 45 percent of the services provided by humanitarian actors were also accessible to persons with disabilities (Handicap International, 2015, 18).[8]

[8] Figures actually differed between 30 and 45% depending on the sector of activities.

Yet, the 2016 World Humanitarian Summit in Istanbul marked a turning point for translating the CRPD into humanitarian policy. The Summit ended with the launch of the *Humanitarian Disability Charter* by which signatories pledge to: (1) Eliminate all forms of discrimination against persons with disabilities; (2) Promote meaningful participation of persons with disabilities and their representative organizations in humanitarian preparedness and response programs; (3) Ensure protection of persons with disabilities as required by international law; (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. Developed by more than seventy stakeholders in the lead up to the Summit (Charter on Inclusion of Persons with Disabilities in Humanitarian Action, 2016), the *Charter* has meanwhile been endorsed by 260 actors, including not just thirty-two UN member states, UN agencies, and the European Union, but also by NGOs, the International Red Cross/Red Crescent Movement, including the International Committee of the Red Cross, OPDs, and many others (Charter on Inclusion of Persons with Disabilities in Humanitarian Action. 2016). Clearly, this indicates a heightened awareness of and an explicit policy commitment to humanitarian action that is inclusive of persons with disabilities, which, as outlined in the *Charter*, must be "in line with the humanitarian principles of humanity and impartiality, and the human rights principles of inherent dignity, equality and non-discrimination" (Charter on Inclusion of Persons with Disabilities in Humanitarian Action, 2016).[9] Human rights and IHL do not always dovetail, but regarding persons with disabilities they actually do, which at first face seems to make the norm cluster rather robust (ICRC, 2017, 1).

Summing up, the entry into force of the CRPD with its separate Article 11 had fundamental implications for humanitarian action. It demanded from States Parties to reinterpret IHL, refugee law, and emergency frameworks through a human rights lens (OHCHR A/HRC/31/30, 2015, 16). Moreover, the principles of participation, accountability, non-discrimination, and empowerment should be at the center of every human

[9] For example, the CRPD recognizes States Parties' obligations under, inter alia, IHL and HRL and obliges States Parties to ensure the protection and safety of persons with disabilities during armed conflict (see CRPD n.d., 10, Art. 11).

rights-based approach to avoid exclusion and ensure meaningful consultation of persons with disabilities and their representative organizations in humanitarian responses (OHCHR A/HRC/31/30, 2015).

The Committee on the Rights of Persons with Disabilities issued a number of recommendations and concluding observations to clarify the scope of Article 11 (OHCHR A/HRC/31/30, 2015, 4–5). Through its pronouncements, new standards emerged.[10] These include inter alia the responsibility of states to adopt or reform national emergency response plans and protocols, and to mainstream disability in their migration and refugee policies and in all humanitarian aid channels (UN, 2013, 2014a, 2014b, 2015a, 2015b, 2015c, 2015d, 2015e, 2015f; OHCHR, 2015).

The subsequent publication of the non-binding *Humanitarian Disability Charter*, an outcome of the World Humanitarian Summit in 2016, provided an opportunity for states to reaffirm their commitments. Moreover, it gave non-state actors in the humanitarian system the chance to endorse a rights-based understanding of disability in their (non-binding) guidelines and tools.

3.5 Other International Agreements and Policies Relevant to the Protection of Persons with Disabilities

Partly inspired by the CRPD and the *Humanitarian Disability Charter*, recent years have seen the development of even more normative instruments at the international and regional levels that emphasize the importance and obligation to protect and assist persons with disabilities in emergencies. The *Sendai Framework for Disaster Risk Reduction*, the 2030 Sustainable Development Goals, the 2018 *Global Compact on Safe, Orderly and Regular Migration*, and the 2018 *Global Compact on Refugees* all refer to persons with disabilities.

Moreover, arms treaties relevant to disability inclusion in humanitarian action, such as the Convention on Cluster Munitions (2008), refer to the CRPD in their preambles. The Convention on Cluster Munitions recognizes the inherent dignity of cluster munition victims and prohibits

[10] Note that although this is not jurisprudence, it can become part of soft law.

their discrimination (Preamble).[11] Additionally, the Arms Trade Treaty (2014) highlights the duty of states to ensure "adequate care, rehabilitation and social and economic inclusion" faced by victims of armed conflict (Preamble).

The UN Security Council also adopted resolutions that call attention to the specific needs of persons with disabilities (UNSC, 2013, 2015, 2018). In June 2019, it passed its first resolution 2475 (UNSC, 2019) on the situation of persons with disabilities in armed conflict and humanitarian crises. It emphasized the principle of non-discrimination in relation to persons with disabilities in emergencies and situations of armed conflict and further strengthens the normative basis on disability inclusion. Adopted by consensus, UN Security Council Resolution 2475 recognizes the Council's serious concern regarding the disproportionate impact of armed conflict on persons with disabilities and proposes concrete actions to address the barriers faced by the world's largest minority group (Security Council Report, 2019). These actions include involving persons with disabilities in humanitarian action and in conflict prevention, expanding the capacity and knowledge of the rights of and specific needs of persons with disabilities across UN peacekeeping and peacebuilding missions, and improving the system of data collection and reporting on persons with disabilities (UNSC, 2019). The resolution was proceeded by an Arria-Formula Meeting[12] in December 2018 to discuss how to ensure a more inclusive and participatory approach toward persons with disabilities during conflicts and a formal briefing in April 2019 on rights of persons with disabilities in situations of armed conflict (Human Rights Watch, 2019a). During the latter briefing, the Syrian disability rights activist Nujeen Mustafa reported on the devastating human consequences of the Syrian civil war and urged UN member states to do more to ensure that all humanitarian programs reach persons with disabilities (Human Rights

[11] The Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-Personnel Mines and on their Destruction (Ottawa Convention) demands from each state party to provide assistance for the care and rehabilitation, and social and economic reintegration of mine victims. It was adopted in 1997 before the CRPD. Hence, it does not explicitly refer to the CRPD and the new human rights understanding of disability.

[12] Arria-Formula Meetings constitute the most flexible meeting format of the Security Council. Introduced in 1992, it allows Council members to invite specific individuals, organizations, or non-state institutions for an exchange of views (see Security Council Report, 2019).

Watch, 2019b). On the first anniversary of the adoption of Resolution 2475, seventy-nine member states recommitted themselves to strengthening efforts to protect and promote the rights of persons with disabilities in the context of armed conflict (Ruminowicz, 2022, 457).

In addition, the UN Human Rights Council passed a landmark resolution on climate change and human rights in July 2019. The resolution calls on governments to adopt a "comprehensive, integrated, gender-responsive and disability-inclusive approach to climate change adaptation and mitigation policies" (UN General Assembly, 2019, 4). Furthermore, it urges them "to increase the participation of persons with disabilities in climate change responses" at all levels of governance (UN General Assembly A/HRC/41/L.24, 2019, 5).

In summary, the sheer number of normative instruments with explicit reference to persons with disabilities leaves no doubt that a rights-based understanding of disability and the inclusion of persons with disabilities in humanitarian action have been firmly *institutionalized* at the international level. Interestingly, the publication of the CRPD also resulted in the *translation* of its core principles into soft law by the humanitarian sector, which is quite uncommon; usually norms travel from soft to hard law but not the other way around (Lohne & Sandvik, 2017, 14).

Yet, to which extent have humanitarian actors *translated* these binding and non-binding tools into their policies and *implemented* them in practice? Following Deitelhoff and Zimmermann's (2019, 3) conceptualization of norm robustness, the question emerges whether the normative claims of these tools also guide the actions of their subscribers. To answer this question, the following chapter examines the policies of the main donors and humanitarian organizations, given their relative power and influence in shaping humanitarian practice.

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CHAPTER 4

Translating Disability Inclusion into the Humanitarian System

Abstract This chapter studies how the main international actors in the humanitarian system—donors, intergovernmental bodies, and humanitarian organizations—have translated disability inclusion into their policies. After a brief introduction, the second part investigates the policies of the main humanitarian donors. It shows that despite growing attention, donor governments vary considerably in their approaches to disability inclusion and need to improve their translation further. The third part studies translation at the interorganizational level. This part explores how humanitarian organizations work with the four "must-do" action: (1) promote meaningful participation of persons with disabilities, (2) address barriers, (3) exercise data collection and monitoring, and (4) engage in empowerment and capacity building. It reveals that humanitarian organizations only gradually adapt their practices and struggle with considering the diversity of the populations they seek to support. The fourth part of this chapter comparatively describes the measures that individual organizations have taken so far to translate disability inclusion. Finally, a comparative analysis reveals that most donor approaches are too abstract and general for implementation and that the humanitarian organizations need to develop their capacities for disability inclusion further.

Keywords Norm translation · Humanitarian policy · Humanitarian donors · Humanitarian organizations · Comparative policy analysis

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4.1 Introduction

With translation, the number of actors involved in norm development multiplies. In the case of disability inclusion, it is useful to look at donor policies and policies within humanitarian organizations to assess the impact of the norm cluster. With donors, we can ask whether they have ratified the CRPD and endorsed the *Humanitarian Disability Charter*; how much funding they provide; whether they are committed to the Organization for Economic Cooperation and Development's Development Assistance Committee (OECD-DAC) Disability Inclusion Marker and demand gender, age, and disability disaggregated data from the organizations they fund; whether they have an inclusion policy or strategy for humanitarian action; and how they evaluate disability inclusion. With humanitarian organizations, we need to understand how they respond to the CRPD, the *Humanitarian Disability Charter*, and donor inclusion policies, as well as how their internal policies reflect and incorporate inclusion and whether and how these influence programming and evaluation.

4.2 Translation into Donor Government Policies

Sufficient funding is indispensable for principled and inclusive humanitarian action. In 2020, the largest donors were the United States, Germany, the European Union, and the United Kingdom, which each spent at least USD 1.6 billion on humanitarian aid. They accounted for almost 89% of all funding from the OECD-DAC member states.[1] Significant but smaller donors were, in descending order, Canada, Switzerland, Sweden, Australia, Norway, Japan, Denmark, the Netherlands, and Belgium.[2] Most of them officially recognize persons with disabilities as a

[1] The DAC is a donor government forum for development and humanitarian issues at the OECD. DAC donors also carry out peer evaluations of each other (see OECD, n.d.a, n.d.b).

[2] The World Bank is another significant donor that strongly supports disability-inclusive disaster risk management and development. In 2022, it updated its "Disability Inclusion and Accountability Framework" (Mcclain-Nhlapo et al., 2022). In this section, we only focus on those donors that are formally entitled to sign and ratify the CRPD to assess in how far they meet their obligations. These donors are members of the World Bank. Unlike the European Union, a regional organization, the World Bank, a multilateral organization, cannot sign and ratify the CRPD.

group in need of protection and assistance. But to which extent do they embrace a human rights-based model of disability inclusion in humanitarian action and endorse the principles of participation, accountability, non-discrimination, and empowerment?

4.2.1 United States

The United States is by far the largest humanitarian donor. In 2020, it spent USD 8.8 billion on humanitarian aid worldwide (OECD, n.d.b). Yet, it is one of four countries which have signed, but not ratified, the CRPD.[3] This is not surprising given that the United States "has one of the worst treaty ratification records in the world" (Kanter, 2019, 302). In fact, of nine core human rights treaties, it has ratified only three (Kanter, 2019, 301).[4] Nevertheless, the United States Agency for International Development's (USAID) initial disability policy is from 1991. At that time, it was the first donor policy on disability and focused on non-discrimination. The United States has also played an active role in the CRPD negotiations and has passed quite a number of federal civil rights laws to ensure equal opportunity for people with disabilities (American Journal of International Law, 2007). The US State Department has a dedicated disability rights team to encourage and assist foreign governments and civil society organizations to increase their commitment and capacity to protect the rights, and ensure the inclusion and full participation of, persons with disabilities. It strives to make disability rights and integral part of US foreign policy and foreign assistance.[5]

It is therefore not surprising that the US Bureau of Population, Refugees and Migration, the humanitarian bureau of the State Department, recognizes persons with disabilities as an 'at-risk' population and encourages its international humanitarian partner organizations, such as the United Nations High Commissioner for Refugees (UNHCR),

[3] The other countries are Lebanon, Tajikistan, and Tonga.

[4] International Convention on the Elimination of Racial Discrimination in 1994, the International Covenant on Civil and Political Rights in 1992, and the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment in 1987.

[5] US Department of State, "Promoting the Rights of Persons with Disabilities". Fact Sheet, Bureau of Democracy, Human Rights, and Labor, 20 January 2021, retrieved 24 July 2023, from https://www.state.gov/promoting-the-rights-of-persons-with-disabilities/.

the International Organization for Migration (IOM), the International Committee of the Red Cross, the United Nations Children's Fund (UNICEF), and NGOs, to consider their particular and shared vulnerabilities. This entails investing additional resources to ensure that persons with disabilities "are engaged in, participate, and contribute to humanitarian programming" (US Department of State, 2021). Similarly, the USAID Office of Foreign Disaster Assistance (OFDA)—now part of the Bureau of Humanitarian Affairs (BHA)—requires all disaster programming to incorporate measures on disability inclusion in design, implementation, monitoring, and evaluation. Partners must demonstrate a comprehensive and consistent approach for disability inclusion at all stages of the program cycle and are obliged to give detailed descriptions in their applications (USAID, 2022, 22–23). Furthermore, USAID has established compulsory standards for any new or renovation construction project to allow access by persons with disabilities (USAID, 2019). In other key policy documents, for example, the first-ever US Strategy on Women, Peace, and Security (2020), USAID commits itself to frequent consultations with women's organizations in countries affected by crisis and conflict, including organizations of women with disabilities (USAID, 2020). The United States also endorsed the *Humanitarian Disability Charter* in 2019, albeit with the additional statement, that it does so "with the understanding … that the Document is not legally binding".[6] In practice, it strongly encourages the inclusion of persons with disabilities in its humanitarian policies and gives particular attention to the participation of persons with disabilities in US-funded programs (USAID, 2019, 16). Currently, USAID is revising its disability policy that will lay out its vision for the coming years. Yet, details have not become public at the time of writing.

Overall, the lack of ratification of the CRPD must not be interpreted as a formal rejection of the norms enshrined in the Convention. It is rather a reflection of a historical relationship of the United States with international human rights treaties that some authors attribute to features in its constitutional system (Bradley, 2010). Although its non-ratification neither fosters ratification by other states nor acceptance by non-state actors, it does not necessarily imply a low level of norm robustness at the national level in the United States.

[6] See http://humanitariandisabilitycharter.org/.

4.2.2 Germany

Germany is the second largest humanitarian donor. In 2020, it spent USD 3 billion on humanitarian assistance (OECD, n.d.b). Germany was one of the first countries to sign the CRPD in March 2007 and ratified it in February 2009. In addition, it is one of 106 parties that have ratified the CRPD Optional Protocol, which establishes procedures for individual and group complaints on violations of the CRPD. Furthermore, it endorsed the *Humanitarian Disability Charter* and other normative tools relevant to the protection of persons with disabilities in situations of risk and humanitarian emergencies and financially supported the development of the *IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action*. In 2019, it voted in favor of the groundbreaking UN Security Council Resolution 2475 on Protection of Persons with Disabilities in Conflict (UNSC, 2019).

The German Federal Foreign Office (GFFO) is Germany's humanitarian donor. It functions at arm length's distance from the Ministry of Development Cooperation. The 2019–2023 Strategy for Humanitarian Assistance Abroad commits Germany to disability-inclusive humanitarian action, encourages the participation of persons with disabilities "in all stages of the programme cycle", and advocates for the creation of effective monitoring mechanisms in humanitarian aid that are accessible to everyone (GFFO, 2019, 41). The German Humanitarian Strategy also underlines that "[a]ffected populations must, to a greater extent, be treated as active agents rather than passive recipients of assistance. This applies particularly to women, young people and persons with disabilities, whose inclusion is particularly limited in most crisis contexts" (GFFO, 2019, 10). The German Federal Foreign Office also integrates disability into other sector-specific strategies, including food security, water, sanitation, and hygiene (WASH), and health.[7]

[7] German Federal Foreign Office (2014) *Grundsätze, Kriterien und Best Practices im Aktionsfeld humanitärer Ernährungshilfe – Leitlinien für die Zusammenarbeit des Auswärtigen Amts und seiner Partner in der humanitären Hilfe* [Principles, Criteria and Best Practices in the Field of Humanitarian Food Aid–Guidelines on Cooperation between the German Federal Foreign Office and its Partners on Food Security in Humanitarian Crises]; German Federal Foreign Office (2016) *Strategie des Auswärtigen Amts im Bereich humanitäre Wasser Sanitärversorgung und Hygiene* [GFFO Humanitarian WASH Strategy]; German Federal Foreign Office (2020) *Strategie des Auswärtigen Amts zur Humanitären Hilfe im Bereich Gesundheit* [GFFO Strategy on Health in Humanitarian

Moreover, Germany introduced a gender, age, and disability marker to ensure disability inclusion in its project-funding application forms for all humanitarian assistance abroad (Agenda for Humanity, 2020). Germany has also revised its project proposal document for humanitarian NGOs, now listing disability as a cross-cutting topic and requests information from humanitarian organizations on how they consider persons with disabilities in their project design. An internal guidance note on disability inclusion supports officers as they review proposals. In addition, Germany promotes disability mainstreaming in humanitarian action and disaster risk reduction through project funding, for example, through the "Leave No One Behind" project series. Together with Jordan, Germany will also co-host the 2025 Global Disability Summit (Global Disability Summit, n.d.).

Overall, these steps indicate a greater awareness of the needs, rights, and specific requirements of persons with disabilities in humanitarian emergencies, although its impact on actual humanitarian practice is not yet clear. In line with its size as a humanitarian donor, Germany could attempt to play a stronger, more structured and strategic role in disability inclusion, as the United Kingdom has done (see below). To do so, it would need to build on its policy improvements of the last five years and construct a more specific inclusion strategy with timelines, objectives, deliverables, more consistent funding, internal expertise building, regular impact assessments, and lessons learned exercises.

4.2.3 European Union Institutions

In 2020, the European Union was the world's third largest donor of humanitarian assistance, with USD 2.6 billion. The European Union is party to the CRPD and signatory to the *Humanitarian Disability Charter*. In fact, the CRPD is the first international, legally binding human rights convention that is also open to regional integration organizations (Article 44 (1)).

In 2019, the Directorate General for European Civilian Protection and Humanitarian Aid Operations (ECHO) of the European Commission published its guidance note *The Inclusion of Persons with Disabilities in EU-funded Humanitarian Aid Operations* in order to promote disability

Action]. The new German Humanitarian Strategy was about to be published when this book went to print.

inclusion in EU-funded relief operations. This note provides tools "to assess and remove the barriers preventing meaningful access and full and effective participation of persons with disabilities" and gives concrete illustrations and examples for humanitarian partners (ECHO, 2019). In 2021, ECHO also introduced a protection mainstreaming indicator, which includes disability disaggregated data (ECHO, 2021). Since 2019, the European Union also applies the disability marker established by the OECD-DAC to track projects specifically targeting the needs of persons with disabilities or mainstreaming disability throughout the response (European Commission, 2020).

In 2022, 259 projects (70.8% of ECHO-funded projects) had considered and mainstreamed the needs of persons with disabilities (European Commission, 2020), underlining ECHO's role as a trailblazer to disability-inclusive humanitarian action. During his visit to the European Union in March 2022, the Special Rapporteur "was impressed" with ECHO's openness and willingness "to factor relevant disability perspectives into their work and their earnest commitment to implementing the Convention" (UN General Assembly A/HRC/52/32/Add. 1, 2022).

In its most recent *Strategy for the Rights of Persons with Disabilities 2021–2030*, the European Union also underlines that it "aims to ensure that the needs of persons with disabilities are adequately addressed in EU-funded humanitarian aid" (European Commission, 2021, 24). This involves strengthening the involvement of persons with disabilities and cooperation with civil society, supporting capacity building, and improving data collection (European Commission, 2021). The Strategy has a dedicated section (Sect. 6) on promoting the rights of persons with disabilities globally. Therein, the European Union explicitly commits to ensuring that the needs of persons with disabilities are adequately addressed in EU-funded humanitarian aid. The Strategy reflects demands from lobby groups, including the International Disability and Development Consortium (IDDC) and the European Disability Forum (EDF), which advocated for the implementation of the OECD-DAC Disability Inclusion Marker in aid operations funded in the European Union (IDDC, 2019; European Disability Forum, 2020).[8]

[8] IDDC is a global consortium of disability and development NGOs, mainstream NGOs, and OPDs supporting development work in more than 100 countries worldwide (IDDC n.d.).

To facilitate the Strategy's implementation, a guidance note *Leaving No One Behind: Disability Inclusion in EU External Action* followed in March 2023. This guidance note provides tools and methods for implementing disability inclusion throughout international cooperation, including humanitarian action, outlines a policy framework and commitments, gives guidance and examples on designing, implementing, and monitoring inclusive interventions, and serves as signpost to further resources, references, and organizations working for disability inclusion (European Commission, 2023, 7).

4.2.4 United Kingdom

In 2020, the United Kingdom spent USD 1.6 billion on humanitarian funding (OECD, n.d.b). It ratified the CRPD and its Optional Protocol in 2009 and is signatory to the *Humanitarian Disability Charter*. In 2018 and 2019, the United Kingdom led with Poland the negotiations of the draft text of UNSC Resolution 2475 on the disproportionate impact of armed conflict on persons with disabilities (Ruminowicz, 2022, 454). So far, it is the only donor which has taken concrete steps to make disability an integral part of its humanitarian assistance (Ruminowicz, 2022, 455).

In 2018, the UK's Foreign, Commonwealth and Development Office (FCDO; at that time the Department for International Development (DFID)) published a "Strategy for Disability Inclusive Development 2018–23". The document, with the catchy title *Now is the Time*, spells out five concrete deliverables on Humanitarian Action: first, promote the routine, systematic collection and use of age, gender, and disability disaggregated data; second, ensure equitable access to essential humanitarian services for all people with disabilities; third, place greater focus on mental health and psychosocial support; fourth, advocate for the safety and protection of girls, women, boys, and men with disabilities in humanitarian crises; and fifth, pursue reform of the international humanitarian system to ensure disability inclusion is effectively and comprehensively addressed.[9]

[9] Overall, the strategy consists of four main pillars: (1) Inclusive Education; (2) Social Protection; (3) Economic Empowerment; and (4) Humanitarian Action. One section deals with "cross-cutting issues".

In a 2020 evaluation, the FCDO remarked that the COVID-19 pandemic had complicated the timely implementation of the Strategy. Yet, it indicated progress toward disability inclusion in a number of fields (FCDO, 2020, 17). Particularly, it highlighted successes in the area of systematic collection and use of disaggregated data on disability, for example, in Humanitarian Response Plans (FCDO, 2020, 19).[10] Thanks to the introduction of a "payment by results indicator" on disability data collection, the United Kingdom pressures leading UN agencies to make disability inclusion an intrinsic part of their programs (DFID, 2018, 7). The Delivery Plan does not explicitly mention NGOs, but they will have to shift their practices and become inclusive when they collaborate with UN agencies.

Moreover, the United Kingdom plans to introduce a separate section on inclusion in its reporting framework and actively strives to improve the evidence base, for example, by allocating an additional £5 million (USD 6.8 million) to test innovative approaches to disability-inclusive humanitarian responses (FCDO, 2020, 17). At the international level, the United Kingdom successfully championed the inclusion of psychosocial support in the Global Compact on Refugees and in the UNHCR updated guidance on inclusion (FCDO, 2020, 19). The new FCDO Inclusion Strategy, released in February 2022, intends to achieve no less than equitable access to essential services for all persons with disabilities affected by crises by 2030 (FCDO, 2020, 28).

Overall, the United Kingdom has the most coherent approach to disability inclusion of all donors and promotes the implementation of inclusive programs and projects through (1) incentives, in particular financial ones, (2) persuasion, and (3) socialization (Finnemore & Hollis, 2016, 449). Worryingly, in 2021, the UK government cut its humanitarian funding by the most of any major Western country (Wintour, 2021; Worley, 2021).[11] Clearly, without reliable funding it will become

[10] Coordinated by OCHA, humanitarian organizations jointly prepare these plans to address an ongoing emergency for specific countries or regions based on so-called Humanitarian Needs Overviews. Humanitarian Response Plans articulate "the shared vision of how to respond to the assessed and expressed needs of the affected population" (OCHA n.d.).

[11] Spending for humanitarian assistance decreased from £1,481 million (USD 1,825 million) in 2020 to £719 million (USD 886 million) in 2021 (Save the Children, 2022).

harder for humanitarian organizations, especially small or medium-sized humanitarian NGOs, to shift to a more disability-inclusive approach.[12]

4.2.5 Japan

Japan spent USD 403 million on humanitarian assistance in 2020, making it the ninth largest humanitarian donor. Taking development funding into account, it is the fifth largest donor country. Japan has ratified the CRPD and is signatory to the *Humanitarian Disability Charter*. Unlike most other donor states, Japan is a disaster-prone country. It has experienced countless natural disasters, such as typhoons, earthquakes, and tsunamis (Ministry of Foreign Affairs of Japan, 2023). Unsurprisingly, Japan gives special attention to disaster risk reduction in its humanitarian assistance (European Parliament, 2016, 2). In 2015, Japan hosted the Third UN Conference on Disaster Risk Reduction, which adopted the *Sendai Framework for Disaster Risk Reduction 2015–2030*. The *Sendai Framework* refers to persons with disabilities numerous times, for example, when stressing their critical role "in the assessment of disaster risk and in designing and implementing plans tailored to their specific requirements" (UN, 2015, 23).

Furthermore, Japan's national legislation contains numerous provisions relevant to the protection of persons with disabilities in the event of a disaster (UN, 2017, 16). Yet, there is little information on any commitments regarding the inclusion of persons with disabilities in its humanitarian assistance abroad. Japan also has not updated its Humanitarian Aid Policy since 2011 and does not mention "persons with disabilities" or any other 'at-risk' group, including children, women and girls, single-headed households, older people, or LGBTQI+. Neither does

[12] An example of the influence of a budget cut comes from HI's work in South Sudan (HI, 2023, 3). HI's work on disability inclusion and mental health in FCDO's Humanitarian Assistance and Resilience program in South Sudan was brought to an unexpected end in March 2023 due to funding cuts. These cuts came after a series of short contract extensions and bridge funding that were initially planned by FCDO to allow the activities to continue until a new successor program could begin. As a result, HI's activities had to stop and continuity to any future program has not been achieved. These cuts came at a time when the 2023 South Sudan Humanitarian Needs Overview (HNO) indicated that more than 9.4 million people are in need of humanitarian assistance, of which at least 1.5 million (16%) were people with disabilities. The FCDO's own equalities impact assessment shows that its cuts have negatively affected disability inclusion in South Sudan. Still, more cuts may occur in the aftermath of COVID-19 and Brexit.

Japan's state report to the Committee on the Rights of Persons with Disabilities refer to measures that could strengthen disability inclusion in humanitarian assistance abroad.

Nevertheless, Japan strongly supports strengthening coordination between humanitarian assistance and development as well as the implementation of the "Build Back Better" concept (European Parliament, 2016, 2).[13] Moreover, the Japanese International Cooperation Agency (JICA), which is also responsible for emergency disaster relief, has *Thematic Guidelines on Disability and Development* that focus on empowerment and mainstreaming of persons with disabilities (JICA, 2009, updated in 2015). Reference to persons with disabilities can also be found in its 2018 *White Paper on Development Cooperation* and in its 2020 Annual Report. These documents provide examples of Japan's support to persons with disabilities, for instance, by improving early detection and early medical treatment system for children with disabilities in Palestine (Ministry of Foreign Affairs of Japan, 2018, 56), or cooperating with the Department of Refugee Affairs of the Palestine Liberation Organization to enable participation of persons with disabilities in refugee camps (JICA, 2020, 37). Yet, none of these documents indicates an overall strategic approach toward disability inclusion in Japan's humanitarian assistance abroad.

4.2.6 *Other Donor Countries and Their Humanitarian Assistance Abroad*

Besides these major donors, other countries spent each between USD 591 million (Canada) to USD 220 million (Belgium) on humanitarian action in 2020 (OECD, n.d.b). All of them have ratified the CRPD and are signatory to the *Humanitarian Disability Charter*.

Two Nordic states—Norway and Denmark—emphasize their human rights perspective to humanitarian action, and list persons with disabilities as a "vulnerable" or "at-risk" group that deserves attention in humanitarian crises (e.g., Norwegian Ministry of Foreign Affairs, 2018). Norway has stepped up its efforts to become more disability-inclusive in recent years by making reporting on inclusion mandatory for its funded operations and by requiring organizations to say how they plan

[13] "Building Back Better is an approach to post-disaster recovery that reduces vulnerability to future disasters and builds community resilience to address physical, social, environmental, and economic vulnerabilities and shocks" (Global Facility for Disaster Reduction and Recovery, n.d., 2).

to include persons with disabilities (European Disability Forum, n.d.b). Moreover, Norway was one of the rotating co-chairs of the Global Action on Disability (GLAD) Network—a donor coordination network, which promotes disability-inclusive development and humanitarian action—and hosted the 2022 Global Disability Summit (European Disability Forum, n.d.b). Denmark's new strategy for development cooperation *The World We Share* (2021–2025: 14) strives to secure "the rights and dignity of marginalised groups" by fighting "discrimination, stigma, and persecution of minority groups" and explicitly pursues the objective to "provide a voice for persons with disabilities" (Ministry of Foreign Affairs of Denmark, n.d.).

Finland is not among the ten largest humanitarian donors. Yet, since 2014, it "has consistently contributed the largest share of its Official Development Assistance (ODA) to disability-inclusive aid projects" (Walton, 2020, 10).[14] Indeed, Finland's humanitarian policy focuses on vulnerable groups and supports greater inclusion of persons with disabilities (Ministry of Foreign Affairs of Finland, n.d.). Despite its relatively small size as an international donor, Finland has become one of the leading countries supporting disability inclusion.

Along with Finland, Australia, Sweden, and Belgium, Canada appears in the top five in terms of its share of disability-inclusive ODA. Between 2014 and 2018, it contributed between 2.6 and 1.5% of its ODA to disability inclusion (Walton, 2020, 11). However, Canada, just like Sweden and Switzerland, does not explicitly mention persons with disabilities in its official information on humanitarian assistance. The strategic priorities of these three countries lie in promoting gender equality, gender-sensitive programming, women's empowerment, and protection from gender-based violence, and in the case of Switzerland, more broadly on the protection of the civilian population (Government of Canada 2020; Ministry of Foreign Affairs of Sweden, 2020; Schweizerische Eidgenossenschaft, 2021). Switzerland, with support from CBM, has nevertheless initiated a national assessment of the CRPD implementation with a focus on disability inclusiveness of development and humanitarian aid as a first step to align its humanitarian funding and policies with global standards (CBM Switzerland, 2021; European Disability Forum, n.d.a).

[14] ODA comprises all aid reported to the OECD, including humanitarian assistance. Figures that clearly distinguish between development and humanitarian aid are not available.

The Netherlands requires its partners to implement the *Humanitarian Inclusion Standards for Older People and People with Disabilities* and to report their results in compliance with these minimum standards (Dutch Ministry of Foreign Affairs, 2019, 12). However, like most other donors, it does not have a detailed disability inclusion strategy.

Australia was one of the most committed supporters of disability inclusion in humanitarian assistance and, as mentioned, ranks among the five most disability inclusion-focused donor countries (Walton, 2020, 11).It was one of the first donor countries to have a stand-alone strategy for making development assistance and humanitarian action disability-inclusive. Its first strategy *Development for All: Towards a Disability-Inclusive Australian Aid Program* was launched in 2009 (Dodds & Clarke, 2022). In 2015, the Department of Foreign Affairs and Trade (DFAT) developed a *Strategy for Strengthening Disability Inclusive Development in Australia's Aid Program* (2015) with consistent core funding of AUD 12.9 million (approximately USD 8.5 million) per year (ADDC and CBM, 2022, 3). It named disability as one of five priority areas in its 2016 Humanitarian Strategy. The government committed itself to three main objectives: (1) supporting inclusive humanitarian assistance and disaster risk reduction by considering and including persons with disabilities in disaster risk reduction and humanitarian planning; (2) working to integrate disability into respective response frameworks; (3) and building the disaster resilience of persons with disabilities through programs and partnerships in the Indo-Pacific region.[15] Moreover, Australia helped to establish the GLAD Network. In a number of ways, Australia supports the inclusion for persons with disabilities in its humanitarian assistance, for example, by promoting rehabilitation services and through research on protecting persons with disabilities in camps for internally displaced persons and refugees (Australian Government Department of Foreign Affairs & Trade, 2015, 24). As part of the Australian Humanitarian Partnership Rohingya Refugee response in Bangladesh, for instance, nine Self-Help Groups and Disability Support Committees formed to represent the rights and voices of persons with disabilities (Government of Australia, 2023, 3). Together with the European Union (in particular ECHO), Finland, Germany, and Luxemburg, Australia also funded the formulation of the *IASC Guidelines on Inclusion of Persons with Disabilities in*

[15] See DFAT (2015, 25). There was no information available on disability inclusion in the humanitarian strategies of Belgium, Saudi Arabia, and the United Arab Emirates.

Humanitarian Action (IASC, 2019b). Recently, however, Australia has reduced its core budget for disability inclusion by 25%. In 2020–2021, the government allocated AUD 12.1 million (around USD 7.9 million) to disability inclusion in its aid program, but decreased the amount to AUD 9.6 million (around USD 6.3 million) in 2021–2022 and 2022–2023 (ADDC and CBM, 2022, 4; CBM Global, 2022). Furthermore, the development of a new *Development for All* Strategy has stagnated because numerous disability inclusion roles within DFAT remained unfulfilled for long periods throughout 2020 and 2021 (ibid). Australia is now left without a strategic vision on disability-inclusive humanitarian action.

Table 4.1 summarizes the findings of this section. In the next section, we will explore how the humanitarian sector has responded to the changing donor policies and the extent to which the emergence of the *IASC Guidelines* have strengthened the robustness of disability inclusion as a human rights issue at the interorganizational level. Subsequently, we will look at the ways in which individual humanitarian organizations have translated the disability norm cluster.

4.3 Translating the Inclusion Norm Cluster at the Interorganizational Level

This section examines the translation of the inclusion norm cluster at the interorganizational level of the humanitarian sector. When donors update their policies to make disability a more integral part of humanitarian assistance and a requirement for funding humanitarian organizations, they can influence the humanitarian sector in various ways. They can, for example, promote inclusion through their reporting frameworks, setting objectives, developing gender, age, and disability markers—or adapting the OECD-DAC disability inclusion marker, demanding evaluations, encouraging knowledge sharing of good practices and lessons learned, and supporting research to enhance the evidence base. In these ways, donors can push humanitarian organizations and their networks to become more disability-inclusive, although virtually always more work is necessary to translate these demands into a concrete policy agenda and implementation.

In general, the humanitarian sector has undergone a remarkable professionalization since aid agencies began to expand "their activities from emergency relief to include goals such as development, postconflict reconstruction, peacebuilding and human rights" (Barnett, 2018, 314). This

Table 4.1 Overview of donor positions on disability-inclusive Humanitarian Action, in descending order based on the amount of overall funding

Largest donor countries	*CRPD states party*	*Endorsed humanitarian disability charter*	*Amount of overall funding in 2020 (US$ million)*	*Committed to using OECD-DAC disability inclusion marker*	*Demand age, gender, disability disaggregated data from partners*	*Inclusion strategy or policy on disability inclusion in humanitarian action*	*Evaluations on disability inclusion in operations funded*
USA	No	Yes	8,835	No information available	Yes	No	No information available
Germany	Yes	Yes	2,971	Yes	No (only age and gender, but indication of the share of persons with disabilities in target group required)	No	No information available
EU Institutions	Yes	Yes	2,577	Yes	Yes	Yes, a general disability strategy with a dedicated section on promoting the rights of persons with disabilities globally, as well as complementary guidance notes on "Disability Inclusion in EU External Action" (2023)' and on the "Inclusion of Persons with Disabilities in EU-funded humanitarian Aid Operations (2019)	No information available

(continued)

Table 4.1 (continued)

Largest donor countries	*CRPD states party*	*Endorsed humanitarian disability charter*	*Amount of overall funding in 2020 (US$ million)*	*Committed to using OECD-DAC disability inclusion marker*	*Demand age, gender, disability disaggregated data from partners*	*Inclusion strategy or policy on disability inclusion in humanitarian action*	*Evaluations on disability inclusion in operations funded*
UK	Yes	Yes	1,631	Yes	Yes	Yes	Yes
Japan	Yes	Yes	403	No	No information available	No	No information available
Canada	Yes	Yes	591	Yes	Yes	No	No information available
Switzerland	Yes	Yes	588	Yes	No information available	No	No information available
Sweden	Yes	Yes	540	Yes	No (only age and gender)	No	Yes
Australia	Yes	Yes	476	Yes	Yes	Yes, but expired in 2021	Yes
Norway	Yes	Yes	473	Yes	Yes (albeit with the caveat "where data is available")	No	No information available

Largest donor countries	*CRPD states party*	*Endorsed humanitarian disability charter*	*Amount of overall funding in 2020 (US$ million)*	*Committed to using OECD-DAC disability inclusion marker*	*Demand age, gender, disability disaggregated data from partners*	*Inclusion strategy or policy on disability inclusion in humanitarian action*	*Evaluations on disability inclusion in operations funded*
Denmark	Yes	Yes	375	Yes	No information available	No, but emphasis on protecting the rights of girls and women along with vulnerable and marginalized groups in its general strategy for development cooperation	No information available
Netherlands	Yes	Yes	351	No	No (only age and gender)	No	No information available

professionalization went hand in hand with the publication of new standards and guidelines that aim to inform humanitarian action, improve its effectiveness, and enhance accountability toward affected populations.[16] The most prominent are *The Code of Conduct for the International Red Cross and Red Crescent Movement and NGOs in Disaster Relief*, the *Core Humanitarian Standard*, and the *Sphere Humanitarian Charter and Minimum Standards in Humanitarian Response* ("Sphere Handbook"). In addition to these general standards, which are now so commonly applied in the humanitarian sectors that they can be considered a form of soft law, the IASC endorsed a variety of specific tools, for example, the *Gender Handbook in Humanitarian Action* (2006), *Guidelines on Mental Health and Psychosocial Support in Emergency Settings* (2007), and the *Framework on Durable Solutions for Internally Displaced Persons* (2010). However, none of these explicitly highlighted persons with disabilities, thus inadvertently contributing to their invisibility and neglect in humanitarian action.

This changed when the UN Secretary-General released his 2016 *Agenda for Humanity* before the World Humanitarian Summit. The *Agenda for Humanity* took a page from the *2030 Agenda for Sustainable Development* and its Sustainable Development Goals, when it used the concept *Leave No One Behind*, which entailed the commitment to reach everyone in situations of conflict, disaster, vulnerability, and risk, including persons with disabilities. Soon after the Summit and concomitant launch of the *Humanitarian Disability Charter*, general and sector-specific standards and policy frameworks with a clear disability focus emerged. These include the *Humanitarian Inclusion Standards for Older People and People with Disabilities* (Age and Disability Consortium, 2018), the *Disability Inclusion and Accountability Framework* of the World Bank (World Bank Group, 2018), and the *UN Disability Inclusion Strategy* (UN, n.d.).

Furthermore, seven UN entities designed the *Guidance on Strengthening Disability Inclusion in Humanitarian Needs Assessments and Response Plans* (2019) with support from DFID.[17] This Guidance details

[16] For a discussion on the relationship of humanitarianism and human rights, see Barnett (2018).

[17] These are UNICEF, the World Food Programme (WFP), UNHCR, OCHA, IOM, WHO, and the Central Emergency Response Fund (CERF). CERF is a global revolving fund, managed by OCHA, that donors replenish annually. Recently, it added a grant

concrete steps for including persons with disabilities in the Humanitarian Needs Overview process and concludes with a comprehensive annex, which offers tips on conducting inclusive key informant interviews, introduces disability data survey instruments, and explains their applicability in humanitarian settings. Moreover, it gives examples of existing needs assessment tools and output-level indicators and contains key resources for inclusion of persons with disabilities (DFID, 2019).

In a parallel process, the Sphere Project on Minimum Standards in Humanitarian Action updated its widely used handbook with minimum standards for humanitarian action. The 2018 edition also focuses on the inclusion of persons with disabilities in humanitarian action and promotes the collection and use of disaggregated data by disability status (Sphere Association, 2018).[18]

In 2015, the International Federation of Red Cross and Red Crescent Societies (IFRC) adopted its Strategic Framework on Disability Inclusion. The Framework outlines three core objectives: (1) ensure that all actions, policies, and internal practices are non-discriminatory toward persons with disabilities; (2) increase the participation of persons with disabilities across the Movement; and (3) promote disability-inclusive practices (Council of Delegates of the International Red Cross and Red Crescent Movement, 2015).

In addition, the International Committee of the Red Cross released its *Vision 2030 on Disability* in 2020, providing a self-critical reflection of its inclusion record, and explicitly remarks that, "we have been slow in implementing disability-inclusive programming and activities in our humanitarian action" (ICRC, 2020, 4). To generate change, the International Committee of the Red Cross seeks to adapt its practices through the routine collection, analysis, and use of data disaggregated by disability (as well as by gender and age), the recruitment and integration of staff with disabilities, and the accessibility of headquarters and delegations (ICRC, 2020). In 2022, it published its inclusive programming policy (ICRC, 2022).

The most influential tool to guide disability-inclusive humanitarian action is the 2019 *IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action*. Developed in a participatory and inclusive

facility. Country-Based Pooled Funds function in a similar way as CERF but only for a specific country.

[18] This edition includes the *Core Humanitarian Standard*, another general standard, which consists of nine commitments to enhance the quality, responsiveness, and accountability of humanitarian action.

process, the *IASC Guidelines* reflect the input of more than six hundred stakeholders across the disability, humanitarian, and development sectors. These stakeholders participated in monthly meetings, global, regional, and thematic consultations, and technical workshops as well as an online survey. A time-bound Task Team on Inclusion of Persons with Disabilities in Humanitarian Action consisting of a diverse membership from seventy-two organizations and public entities participated in the drafting process (IASC, 2018). With the publication of the *IASC Guidelines*, the Task Team dissolved (see Table 4.2).

The *IASC Guidelines* have now been translated into Arabic, Spanish, French, and their respective braille and easy-to-read versions. They define

Table 4.2 Organizational changes in disability inclusion at the global level

With the end of Task Team, a new Reference Group on Inclusion of Persons with Disabilities in Humanitarian Action (usually shortened to Disability Reference Group—DRG) established itself in 2020 to advance disability-inclusive humanitarian action. The DRG is a central platform to support the dissemination of the *IASC Guidelines* and other guidance materials (DRG, 2022, 1–2). Its work rests on three pillars, namely: (1) operationalization; (2) participation; and (3) integration. The first pillar is concerned with the operationalization of guidelines and frameworks for disability-inclusive humanitarian action through technical support. The second one aims to strengthen the participation of OPDs in humanitarian action. Finally, the third pillar seeks to integrate, i.e., mainstream inclusion of persons with disabilities across global processes, including setting priorities for the IASC work plans. The DRG is not an associated entity of the IASC but the three DRG co-chairs, the International Disability Alliance (IDA), CBM Global, and UNICEF, maintain working relations with the IASC Task Force 2 on Accountability to Affected People
The IASC Task Force 2—co-chaired by IFRC, WFP, and the Core Humanitarian Standard Alliance—works toward systematic participation of affected communities, as well as timely and relevant response to feedback and needs voiced by affected communities. The Task Force is currently developing a plan to engage with donors. Yet, it is still too early to assess its impact.[a]

[a]The work of this Task Force builds on the outputs of the Results Group 2 on Accountability and Inclusion, co-led by UNICEF and UNHCR. The Results Groups worked under the Operational Policy and Advocacy Group (OPAG), a forum driving the normative and strategic policy work of the Inter-Agency Standing Committee. They were tasked to deliver normative outputs and guidance to humanitarian actors in cross-cutting issue areas, including (1) Operational Response, (2) Accountability and Inclusion, (3) Collective Advocacy, (4) Humanitarian-Development Cooperation, and (5) Humanitarian Financing (IASC 2019c, 8–9). Results Group 2 established an accountability and inclusion portal, a service directory with information on who is doing what and where on accountability and inclusion (see IASC Accountability and Inclusion Resources Portal, n.d.), a results tracker to measure collective accountability and inclusion, and an accountability framework for field leaders to ensure that collective responses are accountable and inclusive. The Result Group 2 on Accountability and Inclusion completed its mandate on 31 March 2022.

four objectives: (1) provide practical guidance on disability inclusion in humanitarian programming and coordination; (2) increase the capacity of humanitarian actors; (3) raise their awareness on their accountability to include persons with disabilities; and (4) increase the participation of persons with disabilities in preparedness, response, and recovery. In short, "they are designed to promote the implementation of quality humanitarian programmes … and to establish and increase both the inclusion of persons with disabilities and their meaningful participation in all decisions that concern them" (IASC, 2019a, 1).

More than just being a practical tool for aid workers, the *IASC Guidelines* also contribute to clarifying the meaning of the international norms on disability inclusion for daily practice and describe how they relate to and build on existing and more general standards and norms.[19] They explicitly refer to the CRPD and its Article 11 and they contribute to a corpus of soft law on disability inclusion. In doing so, the *IASC Guidelines* further reinforce the *institutionalization* of a rights-based understanding of disability in humanitarian action at the international level. Crucially, they advocate for a twin-track approach that combines inclusive mainstream programs with targeted interventions for persons with disabilities. Furthermore, they spell out the four "must-do" actions, which apply to all humanitarian sectors and contexts namely: (1) promote meaningful participation; (2) remove barriers; (3) empower persons with disabilities and support them in developing their capacities; and (4) disaggregate data for monitoring inclusion.

Each of these four actions relates to at least one relevant Article of the CRPD. For example, Article 19 defines the right to independent living and inclusion in the community; Article 29 introduces the right to participation in political and public life; Article 9 on Accessibility demands the identification and elimination of obstacles and barriers; Article 10 guarantees the right to life, which in humanitarian crises, often depends on the absence of barriers to access life-saving assistance; Article 31 on Statistics and Data Collection demands disaggregated data to assess the implementation of the obligations under the CRPD. Although there is no explicit article on empowering and supporting persons with disabilities, it is of course the thrust of the CRPD and can in particular be derived from Articles 3 and 4 on general principles and general obligations.

[19] Such as the *Core Humanitarian Standard*, *Sphere Handbook*, and *Humanitarian Inclusion Standards for Older People and People with Disabilities*.

The four "must-do" actions clearly show that the disability inclusion norm, like many others, consists of a cluster of (component) norms. Article 11 on the protection of persons with disabilities in Situations of Risk and Humanitarian Emergencies cannot become effective without considering the other relevant articles of the CRPD and their translation and implementation. Indeed, it is more accurate—and more conducive for the empirical study of diversity and inclusion—to speak of a "disability inclusion norm cluster" rather than a single disability inclusion norm. The following sections elaborate the four "must-do" actions and indicate persisting gaps in humanitarian practice.

4.3.1 Promoting Meaningful Participation

In line with the CRPD, the *IASC Guidelines* promote the meaningful participation of persons with disabilities in all stages of the response. In concrete terms, persons with disabilities must participate in all processes that assess, plan, design, implement, monitor, or evaluate humanitarian action. Moreover, the *IASC Guidelines* require humanitarian organizations to recruit persons with disabilities as staff, and to collaborate with OPDs (IASC, 2019a, 20). In contexts where OPDs are still absent or scarce, they are required to encourage their establishment. OPDs are usually run by persons with disabilities and aim to represent their interests, raise awareness, and advocate for their rights (IASC, 2019a, 33). Furthermore, OPDs offer a platform for persons with disabilities to articulate their needs and experiences, share information, make claims, promote access and participation in society, and challenge negative beliefs and stigmas (Cobley, 2018, 75–76). However, collaborating with OPDs will not automatically improve the effectiveness and accountability of humanitarian action. First, the mission and goals of the OPDs may not align with the humanitarian principles. Second, they may not represent all persons with disabilities, but only persons with specific types of impairments. Third, OPDs are usually clustered in capitals and may have limited contextual knowledge of the situation and interests of persons with disabilities across the whole country. Fourth, in refugee contexts, OPDs may only represent the interests of persons with disabilities in host communities and not those of the refugees (see CBM et al. 2019).

More generally, research reveals significant knowledge gaps regarding the participation of persons with disabilities in humanitarian crises

(ELRHA, 2021). There is no clear evidence of people with disabilities regularly contributing to decision-making and planning in humanitarian responses. In settings where they do participate, there is hardly any "documented evidence on the impacts and outcomes of increased participation of persons with disabilities in decision-making".In addition, the role and effectiveness of OPDs in enabling meaningful participation is poorly understood (ELRHA, 2020). In some humanitarian settings, persons with disabilities have not been able to form OPDs, which means that humanitarian actors cannot rely on local platforms for cooperation (Funke & Dijkzeul, 2021b, 79). The reasons for the absence of OPDs vary across different humanitarian contexts (Funke & Dijkzeul, 2021b, 78–79). In the camps in Cox's Bazar, for example, the Bangladeshi authorities do not allow the Rohingyas to establish organizations, including OPDs, because they officially consider the Rohingyas "forcibly displaced nationals from Myanmar" instead of refugees. This stance taken by the authorities fosters the continuation of the supposition that the Rohingyas will be able to return to Myanmar soon and therefore do not need to organize themselves. However, informal self-help groups and disability committees have been formed with support of the humanitarian community and financial assistance from Australia (Government of Australia, 2023, 3). But how and to which extent these groups and committees can promote the meaningful participation of persons with disabilities in these camps remains unclear.

At present, humanitarian organizations mainly limit themselves to "engaging" persons with disabilities in the humanitarian response, which entails asking persons with disabilities about their needs and inviting them to attend meetings and consultations (Funke & Dijkzeul, 2021b, 23). Interviews with humanitarian staff from South Sudan reveal that persons with disabilities are rarely involved in program development (Funke & Dijkzeul, 2021a, 29). Moreover, the COVID-19 pandemic contributed to their exclusion in cluster coordination meetings when these shifted to online-only formats, due to limited internet access of smaller NGOs, including OPDs, and/or lack of reasonable facilitation, such as sign language interpreters (Funke & Dijkzeul, 2021a, 30). Furthermore, especially persons with intellectual impairments and/or psychosocial needs are often excluded from the humanitarian response (OCHA, 2021, 31). In Somalia, for instance, "persons with disabilities are not meaningfully consulted regarding access to services, and lack access to feedback mechanisms" (OCHA, 2021, 31).

Undoubtedly, this violates international standards: it is a violation of the obligations of the CRPD that have been translated into these international standards. As mentioned, the CRPD and Humanitarian Inclusion Standards, the *IASC Guidelines*, and related tools demand from humanitarian organizations conscious efforts to involve persons with disabilities, their families, and OPDs in all stages of humanitarian programming (ELRHA, 2020, 26). This often requires significant investments in capacity building and empowerment of persons with disabilities so that they increase their confidence as active contributors to society, learn to organize themselves in disability committees, OPDs, or self-help groups, and can contribute directly to the response (Funke & Dijkzeul, 2021a, 53, 2021b, 43; CBM International, 2019, 11). Simultaneously, humanitarian actors must build their internal capacities on inclusive humanitarian action, which can be resource-intensive and time-consuming.

Renewed efforts in embedding "meaningful participation" of affected populations into humanitarian practice demonstrate that humanitarian organizations (only) gradually adapt their practices (Funke & Dijkzeul, 2021a, 63). Examples include the "participation revolution" work stream of the *Grand Bargain* (2017), which inter alia seeks to develop common standards and a coordinated approach for community engagement and participation with an emphasis on inclusion of the most vulnerable (IASC n.d.) and the participation commitment in the *Core Humanitarian Standard*, which requires the humanitarian response to be based on communication, participation, and feedback. In the light of these broader requirements and ongoing changes in the humanitarian system, it will be considered increasingly inappropriate to exclude persons with disabilities from coordination mechanisms, intersectoral needs assessments and decision-making. Yet, persons with disabilities are not the only ones that are being left behind in humanitarian action. Ideally, humanitarian actors consider the whole diversity of the population and pay attention to underrepresented groups, such as indigenous persons, women and girls, single-headed households, LGBTQI+ persons, or older people or children (IASC, 2019a).[20] These issues all intersect with disability inclusion. Realizing such an ambitious approach to diversity and inclusion requires overcoming several barriers.

[20] The *IASC Guidelines* stress this point in numerous chapters.

4.3.2 *Addressing Barriers*

Persons with disabilities face multiple barriers that increase their vulnerabilities. These barriers derive from negative attitudes, physical obstacles in the environment, poor communication, and from institutionalized practices that discriminate against persons with disabilities (IASC, 2019a, 8). Humanitarian organizations need to identify these attitudinal, environmental, and institutional barriers, as well as corresponding enablers, in different crisis-contexts, and based on these insights, develop specific strategies to facilitate an inclusive response (IASC, 2019a).

The humanitarian community has made some progress in this regard. The work of inclusion-focused NGOs has led to change in reporting about barriers for persons with disabilities.[21] They piloted barriers and facilitator assessments together with UN agencies and clusters in various contexts (e.g., HI and WFP, 2021).[22] Moreover, they actively lobbied for a greater focus on persons with disabilities in the global and country-based Humanitarian Needs Overviews[23] and Humanitarian Response Plans.[24] Since 2020, the Global Humanitarian Needs Overviews increasingly describe specific requirements and persisting needs across all humanitarian sectors. Humanitarian Needs Overviews also have begun to pay closer attention to the barriers that prevent persons with disabilities from accessing services and fully participating in the humanitarian responses.[25] Considering that these Needs Overviews rarely mentioned persons with disabilities before the 2016 Global Humanitarian Summit, this is a step forward. Still, more barrier and facilitator analyses are needed.

[21] In South Sudan, for example, HI established a partnership with IOM for its Displacement Tracking Matrix to undertake an assessment of the level of access to services and barriers faced by persons with disabilities in various locations.

[22] E-Mail exchange with Ulrike Last (HI).

[23] HNOs are a joint needs assessment tool. They support the Humanitarian Country Team—and by extension, all interested actors—in developing a shared understanding of the impact and evolution of a crisis and inform response planning to help people in need (see OCHA Knowledge Base, 2024). Increasingly, the HNOs and HRPs are being combined into the Humanitarian Needs and Response Plans (HNRP).

[24] See footnote 10.

[25] However, the extent to which Humanitarian Needs Overviews in all country operations reflect the needs, risks, and specific requirements of persons with disabilities requires more research.

So far, evaluations, assessments, or case studies on how humanitarian organizations move beyond the identification of barriers and actually address persisting protection gaps and obstacles to inclusion are rare. Field research on the Rohingya refugee response (Funke & Dijkzeul, 2021b) suggests that whereas humanitarian organizations are generally aware of the common and more obvious barriers and multiple forms of discrimination that persons with disabilities experience in the humanitarian response, only limited capacities exist to prevent and overcome them. Organizations and their staff members often lack the expertise, time, or funding to identify, design, and implement strategies to address barriers and mainstream disability into their operations (CBM International et al., 2019, 32). Of course, this is no excuse for excluding persons with disabilities and violating normative commitments. Ideally, this awareness should motivate organizations to train and sensitize their staff on disability-inclusive practices and for donors to make additional funds available for organizations to invest in capacity building. But for many this feels like yet another task on top of many other challenges to their already demanding humanitarian response. The shift from policy translation to actual implementation on the ground is difficult (UN Special Rapporteur on the Rights of Persons with Disabilities, 2018, 30).

4.3.3 Data Collection and Monitoring

Besides participation and the removal of barriers, the collection and use of quantitative and qualitative data on disability is essential for a disability-inclusive humanitarian response (Handicap International, 2021, 2). Although repeatedly mentioned in global standards, guidelines, Humanitarian Needs Overviews and Humanitarian Response Plans, and increasingly demanded by donors, data on disability is often flawed or simply not available (Collinson, 2020, 16). This data should include information on the prevalence of disability within the target population, barriers and enablers of inclusion, the risks of discrimination and marginalization, as well as assessments of the capacities of persons with disabilities to take informed decisions and contribute meaningfully to the response.

Developing countries, where most humanitarian crises occur, tended to focus on a narrow set of impairments, using medical models of disability that have stigmatizing labels and definitions (WHO and World Bank, 2011; UNICEF, 2018, 14). Hence, humanitarian actors usually

could not build on the official country figures that were supposed to measure the prevalence of disability; the definitions and methodologies for the collection of data were not consistent among states. Moreover, data collection can be extremely challenging in insecure regions with limited access and if statistical information is available, it is rarely regularly updated (WHO, 2022, 22).[26] Until recently, many national statistics suggested that the percentage of persons with disabilities is lower than the 16% estimated by WHO (WHO, 2022, 2–3).[27] Even in countries where reliable figures on disability existed, data may no longer be accurate and useful after the outbreak of armed violence or the occurrence of a natural disaster (UNICEF et al., 2017, 7).

In recent years, humanitarian actors have begun to collect their own data on persons with disabilities (Leonard Cheshire and Handicap International, 2018, 5). Yet, until recently, they predominantly used binary "yes–no" questions rather than data collection methods that reflect the multi-dimensional nature of disability (Leonard Cheshire and Handicap International, 2018, 5; see below). Such binary data on disability does not necessarily help aid agencies to gain a better understanding of the specific assistance and protection needs of persons with disabilities, the barriers they encounter, and the services they require, as well as the skills they bring with them.

[26] For example, the last census in what is now South Sudan took place in 2008 (Disability Data Portal, 2024). In the DR Congo, the last census was taken in 1984 (Africanews, 2022).

[27] According to the UN Disability Statistics Database the percentage of persons with disabilities in developing countries is supposedly low. Afghanistan, Angola, the Philippines, and Yemen, for example, claim that no more than 2–3% of their population have some kind of disability. In contrast, in Austria (18.4%), the United States (12.8%), and Canada (13.7%) these figures are significantly higher. Sweden even estimates that the percentage of persons with disabilities amounts to 35.2% (UN Statistics Division, n.d.). Not all countries have provided official figures. As indicated in footnote 1, it is estimated that almost 79% of the Afghan population has a disability (Asia Foundation 2019, 18). However, due to data based on different definitions and methodologies, statistics in the UN Disability Database are not internationally comparable. Interestingly, recent evidence on disability prevalence rates in the Global South are based on internationally comparable data that use the Washington Group Short Set or the Child Functioning Module. These studies tend to show higher prevalence rates than earlier estimates using a variety of measures as in the UN Disability Statistics Database (e.g., Hanass-Hancock et al., 2023b, Mitra & Yap, 2021, UNICEF, 2021). In other words, disability statistics are currently improving, but it is not clear yet whether and how humanitarian organizations are using these statistics.

The Washington Group has developed tools to measure disability in line with the functional approach of the WHO's International Classification of Functioning, Disability, and Health.[28] These tools avoid the term "disability" and instead address only limitations in undertaking basic activities. Originally designed for population censuses and national household surveys, development and humanitarian organizations increasingly use them for their own data collection and analysis purposes.[29] A number of international organizations, including the United Nations Development Programme, the International Labour Organization, UNICEF, WHO, OHCHR, IDA, and IDDC officially endorse the Washington Group Questions as the most suitable tool for producing disaggregated data on disability (Leonard Cheshire and Handicap International, 2018, 7).[30]

The Washington Group Short Set on Functioning (WG-SS) covers six core areas of activity: 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 (Leonard Cheshire and Handicap International, 2018, 7; Washington Group on Disability Statistics, 2021). When more detail is required or where children are concerned, the Washington Group has developed additional tools.[31]

Nevertheless, research on the use of the Washington Group Questions by humanitarian and development actors revealed several pitfalls, which

[28] 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 is a UN city group established under the United Nations Statistical Commission (Washington Group, 2020).

[29] The Humanitarian Inclusion Standards, the Sphere Handbook, and the *IASC Guidelines* advocate for the use of the Washington Group Short Set in humanitarian action.

[30] The production of disaggregated data on disability is usually not a straightforward process. "Researchers need to apply cut-off points (or thresholds) when creating […] disability measures and dividing the data in those who are identified as having a disability and those who are not. The chosen cut-off(s) for the level of functional disability affects estimates of disability prevalence and inequalities in wellbeing between persons with and without disabilities (also referred [to] as disability gaps)" (Hanass-Hancock et al., 2023a, 2).

[31] The Washington Group Short Set on Functioning – Enhanced; Extended Question Set on Functioning; the Washington Group Child Functioning Module (Washington Group on Disability Statistics 2021a). For more tools, see Annex 2 of the *IASC Guidelines* (IASC, 2019b, 192).

should be well understood before requesting or collecting disaggregated data on persons with disabilities in humanitarian crises (Leonard Cheshire and Handicap International, 2018, 29). Most importantly, organizations require guidance and training on how to use these questions. It is crucial that they are not mistaken as a diagnostic tool for individual persons. They should be used exactly as they are prescribed, with translations of the questions verified by the Washington Group. Hence, they should not be used as screening questions for individuals or in isolation from larger surveys or questionnaires. To be effective, they also need to be built into pre-existing data collection methods. In addition, organizations need to possess the skills to analyze the data correctly. Apart from general data literacy skills, a sound understanding of disability and inclusion is vital. Otherwise, their connection to strengthening program design, implementation, and evaluation remains limited (Leonard Cheshire and Handicap International, 2018). Perry (2023a, 25), for example, notices that the WG-SS were not used appropriately in the 2023 South Sudan Humanitarian Needs Overview. Data was "collected using a modified Washington Group methodology, where questions were asked at the household level rather than to individuals, and [analyzed] on a 'severity scale' of 1–5 (none/minimal—stress—severe—extreme—catastrophic) using a wrong interpretation of the Washington Group's guidance" (Perry, 2023b, 25).[32]

As a first step to use disability data properly, the five criteria in Table 4.3 can help humanitarians to assess when to use the WG-SS in their programming. They address the purpose, feasibility, buy-in, quality, and actionability of data disaggregated by disability.

In addition to the collection of quantitative data, humanitarian organizations should facilitate comprehensive barriers and facilitator assessments to understand the views and priorities of persons with disabilities, map the capacities and resources of organizations in the humanitarian response, and monitor the degree to which persons with disabilities have access to assistance, services, and facilities (IASC, 2019a, 23). This usually requires the use of qualitative research methods, such as focus group discussions, key informant interviews, and (participant) observation (IASC, 2019a, 24). Clearly, this is a demanding task but without solid qualitative and

[32] Perry (2023b, 25) also argues that data collection "when implemented poorly with unusable data using an unhelpful analytic framework […] not only produces no result but also hardens the resistance to collecting and using disability data" (ibid).

Table 4.3 Decision tool for the use of the Washington Group short set on functioning in humanitarian programming (O'Reilly et al., 2023)

Will it work?		
Criteria	*Questions to ask when considering implementing the WG-SS*	*Yes/ No*
Purpose	Is there a clear and shared understanding of why these data should be collected, and how the resulting information can contribute to programmatic objectives?	[Yes] [No]
Buy-In	Are key staff involved in the collection, analysis, and use of data willing to implement the WG-SS?	[Yes] [No]
Feasibility	Is disaggregation feasible in the available timeline and implementation context, using the available resources and modality of data collection?	[Yes] [No]
Quality	Is your data collection process capable of implementing quality checks and adapting as required?	[Yes] [No]
Analysis and Action	Is there a plan in place to analyze and use the data to contribute to inclusive programming?	[Yes] [No]

quantitative data it is impossible to identify persons with disabilities, establish their needs, remove barriers, and enable meaningful participation. Coordination cluster leads and humanitarian country teams, who share responsibility for Humanitarian Needs Overviews and Humanitarian Response Plans, should therefore encourage organizations to share their data on disability with other humanitarians in preparing relevant coordination forums and working groups and develop a (joint) strategy at the international and national levels to close data gaps. At present, the humanitarian sector tends to privilege quantitative over qualitative data because the latter is often perceived as being more opaque, less efficient, and less reliable than numbers (Glasman, 2020). Yet, the rapid growth of numerical data does not sufficiently lead to more knowledge on actual needs, attitudes, perceptions, and capacities of crisis-affected individuals, including persons with disabilities.

4.3.4 *Empowerment and Capacity Building*[33]

To ensure the meaningful participation of persons with disabilities in humanitarian action, including their representation in relevant coordination mechanisms, it is central for humanitarian actors, persons with disabilities and their representative organizations to increase their awareness about their rights and strengthen their knowledge of the humanitarian system (Funke & Dijkzeul, 2021b, 79). The *IASC Guidelines* therefore encourage humanitarian organizations to support persons with disabilities in these efforts and to strengthen and extend their capacities, for example, through training, collecting experiences and good practices, and establishing help desks. Simultaneously, they recommend humanitarian organizations to sensitize their staff on the rights of persons with disabilities at all levels throughout the humanitarian response, including first responders, other staff, service providers, and contractors. This means that capacity building is a two-way street that requires both persons with disabilities and humanitarian workers to build their knowledge, skills, and understanding of inclusive humanitarian action (IASC, 2019a, 20).

Usually, disability-focused NGOs, such as HI and CBM, organize training courses, inclusion audits, and provide technical support to mainstream organizations. Simultaneously, they closely work with persons with disabilities and OPDs to build their capacities on the functioning of the humanitarian system and respective coordination structures. In the Rohingya refugee response in Bangladesh, for example, HI and CBM, together with their local partner, the Centre for Disability in Development, include capacity building into their UK- and Australia-funded projects (Funke, 2020; Funke & Dijkzeul, 2021b).

Besides capacity building within a particular funded project or response, new initiatives also emerged at the international level. The Age and Disability Capacity Programme (ADCAP) consortium[34] developed a training model, a handbook, toolkits, templates, and materials on best practices (Hill et al., 2020, 20). Moreover, IDA and IDDC created an intensive training program on the CRPD and the Sustainable

[33] The *IASC Guidelines* mention "empowerment and capacity building" before "data collection and monitoring". Here we decided to change this order because "empowerment and capacity building" is an essential part of and a prerequisite for the previous three "must-do" actions.

[34] ADCAP is an initiative of CBM, Disasterready.org, HI, HelpAge International, IFRC, Oxford Brookes University, and RedR UK.

Development Goals, the so-called Bridge CRPD-SDG training initiative. It aims to support OPDs and disability rights advocates to develop an inclusive and comprehensive CRPD perspective on development (IDA, 2021). For example, in 2019, the initiative organized its first training on Article 11 of the CRPD. The training brought together 38 leaders from the disability rights movement and humanitarian organizations to foster dialogue, cooperation, and exchange among them (Fleury & Ujah, 2020, 13). Participants evaluated the pilot training as extremely positive, and going forward, more trainings shall have an Article 11 focus.[35] In 2023, the United Nations System Staff College (UNSSC) also introduced a self-paced course "United Nations Disability Inclusion Strategy – Putting Words into Action" (UNSSC, 2022). Developed by the Disability Team of the Executive Office of the Secretary-General, the learning module supports UN personnel at all levels to develop a disability-inclusive mindset and take action to promote disability inclusion in their day-to-day work (UNSSC, 2022). With funding from the German Federal Foreign Office, the Disability Reference Group also developed seven training modules to facilitate learning and discussions on disability-inclusive humanitarian action (HI, n.d.).

Nevertheless, caution is needed when promoting capacity building. Drawing on evidence from Nicaragua, Meyers (2014, 405) shows that political empowerment, advocacy training, and efforts to formalize reporting procedures did not resonate with local OPDs. For capacity building measures to be effective and inclusive, they need to be sensitive to the local context and priorities (Meyers, 2016, 7). Otherwise, they create a top-down process by which OPDs merely echo global priorities, risking that local OPDs distance themselves from their members and ultimately "render them ineffective in their specific social and political contexts" (Meyers, 2016, 7).

All in all, the humanitarian sector is making progress with translating the disability norm cluster. Yet, sector-wide policies, guidelines, and standards need to be complemented by the actions of individual organizations.

[35] E-mail correspondence, CBM, 7 August 2019.

4.4 Translating the Inclusion Norm Cluster Within Humanitarian Organizations

The publication of the *IASC Guidelines* and related normative frameworks contributed to a heightened awareness on gaps in disability inclusion. Large humanitarian organizations, such as the UN agencies, the International Committee of the Red Cross and the International Federation of the Red Cross and Red Crescent Societies, with comparatively stable funding sources, have more capacity to design inclusive policies, develop a clear strategy, hire inclusion focal points and in doing so, gradually mainstream disability across their organizations than their smaller implementing partners (Funke & Dijkzeul, 2021a, 55). Many smaller NGOs are struggling to put their commitments on inclusion into policy and action (Funke & Dijkzeul, 2021a, 52). Strikingly, little public information exists on how the largest humanitarian NGOs incorporate disability-inclusive approaches into their work. There is even less information from the many smaller NGOs worldwide. The Norwegian Refugee Council, for instance, admitted that it was still not systematically addressing disability and many other diversity issues across all projects, contexts, and phases of displacement (Atlas Alliance, 2020).

Other NGOs have made more progress. In 2018, Médecins Sans Frontières (MSF) launched an international project on inclusion of persons with disabilities and developed a guideline for MSF field staff to build their capacity (Médecins Sans Frontierès, n.d.). One year later, the International Rescue Committee (IRC) adopted a "Client Responsive Programming Framework", which demands feedback mechanisms to be accessible for all (IRC, 2016). Moreover, country programs are obliged to proactively engage vulnerable groups, including persons with disabilities. Islamic Relief went even further and developed an Operational Framework on Protection and Inclusion. Furthermore, it carried out an internal review to assess progress toward disability-inclusive programming (Alsheikh Ahmed, 2020, 34). Crucially, Islamic Relief also broadened access to the *IASC Guidelines* by facilitating their translation into Arabic (Islamic Relief, 2020, 50). So far, however, there are only few examples of good practices from NGOs; having guidelines and a "Client Response Framework" does not imply that these organizations successfully implement all of their commitments.

In fact, even despite its system-wide *Disability Inclusion Strategy*, the United Nations also needs to improve its performance vis-à-vis persons

with disabilities. A 2020 progress report revealed that although the launch of this *Strategy* has contributed to a change in mindset and values among UN entities and many of them have now taken action on disability inclusion, "improvement is needed for the majority of entities to meet the performance indicators" (UN, 2020, 12). Particularly, the UN organizations need to make greater strides in promoting the meaningful participation of persons with disabilities. Although UN entities are consulting with persons with disabilities and their representative organizations, "such consultations have not been undertaken in a systematic, inclusive and accessible manner" (UN, 2020, 16). Furthermore, they need to step up efforts to remove attitudinal, environmental, and institutional barriers. Only 21% of UN organizations have established or implemented an accessibility policy, and only 18% ensure that their procurement is accessible and disability-inclusive (UN, 2020, 17). Improvement is essential because UN organizations usually play a lead-role in humanitarian coordination at international and country levels. The stronger the leads, the better the coordination clusters can operate.

In other areas, especially data collection, the UN System is more advanced. More than half of the entities (56%) have either integrated disability into their strategic plans—which include indicators that disaggregate data by disability and sex—or are approaching this requirement (UN, 2020, 15). Regarding the building of organizational capacity, the report reveals a mixed picture. While 47% of entities provide learning and training opportunities on disability inclusion, only 4% indicate that the completion of such training was mandatory for staff at all levels (UN, 2020, 21).

Yet, overall, there is a general trend toward changing common practices and entrenched structures so that persons with disabilities can participate more at all levels and stages of the humanitarian response. However, translation at the policy level, though incomplete, is stronger than implementation at the field level (see Chapter 5).

4.5 Comparative Analysis of Norm Translation into Policies and Norm Robustness

The former sections empirically described the various donor and humanitarian policies. This section comparatively analyzes what these forms of translation mean for norm robustness. Table 4.1 shows that despite gradually growing initiatives, donor governments vary considerably in

their approaches to disability inclusion and must improve translation and implementation further. Most approaches are too abstract and general for quick implementation. Except for the United Kingdom, no donor state has a concise up-to-date disability inclusion strategy for its humanitarian assistance.[36] This makes it difficult to measure progress against donors' self-defined objectives. These objectives, if any, are usually "hidden" in a number of different documents, such as white papers, national strategies on disability, general strategies on humanitarian action, and related documents. In concrete terms, this impedes monitoring of the use of disability disaggregated data, implementation of the OECD-DAC disability inclusion marker, overall ODA spending on disability inclusion, donor engagement with OPDs, and human resources used for work on disability. Evaluations on disability inclusion funded by these donors are only infrequently available. Altogether, this leaves humanitarian stakeholders, including persons with disabilities, with patchy and incomplete information on inclusion. As a result, the cumulative impact of donor approaches to inclusion is not high enough. What does this tell us about norm translation and norm robustness?

As stated, norms may strengthen, gain more clarity, or lose relevance (Wunderlich, 2013, 29). Undoubtedly, the adoption of the CRPD strengthened the disability inclusion norm for humanitarian action. Its Article 11 on the protection of persons with disabilities in emergencies created for the first time non-derogable obligations (Motz, 2018, 314). The adoption of the CRPD also led to important donor policy developments and the creation of non-binding tools and guidelines. They underscore a rights-based approach to disability inclusion and provide guidance for donors and other actors on how to implement these obligations into humanitarian practice, for example, through the removal of barriers, collection of disaggregated data, and empowerment and capacity building. At first glance, they firmly *institutionalize* disability as a human rights issue at the international level.

However, each resolution, policy document, and guidance on inclusion also draws attention to the fact that the actual *translation* and *implementation* of the disability inclusion norm are low since its claims

[36] Although it is worth noting that some of these donors, like Finland, have strategies specifically for development assistance. In addition, the *2021–2030 European Union Disability Strategy* emphasizes the European Union's role and responsibilities within humanitarian action in a dedicated section.

do not consistently guide the actions of its addressees. Although most donors refer to persons with disabilities in their policies as an 'at-risk group', they rarely make the inclusion of persons with disabilities a priority in their humanitarian funding. In contrast, many donors do seek to include women and children through their policies and funding (e.g., European Commission, 2020; Government of Canada, 2020). Regarding disability inclusion, though, many policy documents remain astonishingly vague about the best ways to promote the principles of participation, accountability, non-discrimination, and empowerment (e.g., USAID, 2019; Ministry of Foreign Affairs (Japan) 2011). Only the United Kingdom has a precise strategy with clear objectives and deliverables to measure progress (Ruminowicz, 2022, 455; FCDO, 2020), although recent budget cuts for humanitarian action will most likely slow down its implementation. The numbers of ODA also speak for themselves: Despite donor commitments and policy initiatives, overall funding targeted for the purpose of inclusion remains low. Walton found that between 2014 and 2018 "even the five most disability-inclusion focused donors targeted just 3% of their aid to this purpose" (Walton, 2020, 1). Between 2014 and 2018, "projects targeting disability inclusion totaled merely $ 3.2 billion, which represents less than 0.5% of all international aid" (Walton, 2020, 1). Australia—once a leading voice on disability inclusion at the global stage—has significantly weakened its role as a norm entrepreneur by delaying the process of developing a new stand-alone strategy on disability inclusion and through significant cuts in its core disability budget. Hence, the translation of the disability inclusion norm cluster is poor or has been weakened.

Nevertheless, the absence of a detailed disability inclusion strategy does not imply that the donors are indifferent to their legal obligations under the CRPD. Otherwise, the growth in institutionalization at the international level would not have been possible (see UN Women, 2022). As mentioned, Germany lists disability as a cross-cutting topic and requests information from humanitarian organizations on how they consider persons with disabilities in their projects, and it integrates disability into sector-specific strategies. Most other donors, for example Sweden, committed themselves to adopting the OECD-DAC Disability Inclusion Marker, which allows partner organizations to flag whether their ODA spending is disability-inclusive (UN Women, 2022, 4). Similar commitments are reflected in the European *Strategy for the Rights of Persons with Disabilities 2021–2030*.

These examples show that many donors are aware of their central role in promoting the inclusion of persons with disabilities in humanitarian action and are changing their policies, albeit slowly. Some donors, notably the United Kingdom and now also the European Union and Finland, work toward a holistic approach that goes beyond disability inclusion in humanitarian programs. They promote the creation of an accessible and inclusive work environment, and strengthen the internal skills, knowledge, and expertise of their own staff (FCDO, 2020, 23; ECHO, 2019). One of the flagship initiatives of the EU *Strategy for the Rights of Persons with Disabilities 2021–2030,* for example, is the Disability Platform. It comprises experts from all EU member states, 14 civil society organizations, and the European institutions to enhance cooperation between the institutions of the EU member states, the Commission, and civil society on issues relating to disability.

Moreover, some humanitarian donors use their membership in international forums to advocate for disability inclusion. Australia, for example, made disability inclusion a focus in its 2018–2020 term on the UN Human Rights Council, which culminated in the resolution on disability and climate change (Department of Foreign Affairs and Trade, n.d.). Similarly, the European Union intends to "share its strategies and practices on the implementation of the UNCRPD in UN multilateral fora, such as the Human Rights Council, the Commission on the Status of Women, or the Commission of[37] Social Development" (European Commission, 2021, 24). Furthermore, all representations of the European Union around the world, including those in countries affected by crises, now have their own focal points on development and disability (UN General Assembly A/HRC/52/32/Add.1, 2022, 11). In short, donors have begun to use their power of the purse and policies to promote the use of disability inclusion markers in their funding proposals, as well as age, gender, and disability disaggregated data. Yet, in 2018, only 9% of OECD-DAC—marked disability aid "used disability-inclusive keywords in project titles and descriptions" (Walton, 2020, 7). Furthermore, evaluations of projects that promote inclusion and empowerment of persons with disabilities are rare so that the evidence base on progress toward more inclusive humanitarian action remains much too small (Walton, 2020, 7). Indeed, there is rarely any evidence that donors

[37] The European Commission quotes "of" even though it is the Commission for Social Development.

provide funding directly to OPDs (Walton, 2020, 13). A GLAD Network study on meaningful engagement of OPDs in Bangladesh, Kenya, and Nepal found that donors prefer to fund INGOs, which give their funding to national umbrella OPDs or federations. National and local OPDs then receive their funding from those umbrella OPDs or federations. As a result, the roles of local OPDs remain most often confined to project implementation, and to a large extent, only event organization (GLAD Network, 2022, 4). Field research in Cox's Bazar and South Sudan shows that this is still the case because donors either do not know the OPDs well enough or delegate capacity building of OPDs to INGOs and UN organizations (see below).

All in all, the inclusion of persons with disabilities in humanitarian policies is still at a nascent stage. More than 8 years after the launch of the *Humanitarian Disability Charter*, and 17 years after the entry into force of the CRPD most donors are still in the process of *translating* their commitments into a concrete agenda. Although the global estimate is that 16% of the population has a disability, funding rarely succeeds 3% of donor funding. In addition, not having a detailed strategy impedes the translation and implementation of norms. A lack of a detailed strategy on disability is thus a fairly clear example of States Parties not recognizing their legal obligations under the CRPD. As long as donors do not indicate precisely how they promote disability inclusion and allocate sufficient funding, we cannot speak of a robust disability inclusion norm at the international and domestic levels.

Unsurprisingly, there are leaders and laggards in norm translation. While the United Kingdom has a detailed delivery plan, Japan as the ninth largest humanitarian donor, does not specify any systematic efforts in promoting the inclusion of persons with disabilities in its assistance (Ministry of Foreign Affairs of Japan, 2011). Remarkably, this also applies to states, such as Switzerland, which are strong proponents of rights-based approaches in international cooperation but whose humanitarian strategies lack an articulated focus on disability inclusion.

Moreover, the donors' language does not consistently reflect a rights-based approach to inclusion. Some of them still frame persons with disabilities as "particularly vulnerable" who "do not have the same capacities to access water, food or medical care" (Schweizerische Eidgenossenschaft, 2020). Policy Letters of the Netherlands and Norway's Humanitarian Strategy also refer to persons with disabilities as just a vulnerable

group. In 2022, the Committee on the Rights of Persons with Disabilities, for example, criticized Japan for the perpetuation of the medical model of disability across legislation, regulation, and practice and use of derogatory terminology, as well as inaccurate translation of the CRPD into Japanese, particularly of crucial terms, such as "inclusion" (CRPD/C/JPNCO/1 9 September 2022, p. 2). Yet, the Committee did not comment on Japan's humanitarian assistance abroad and only examined its approach to natural disasters when discussing Article 11 obligations. With respect to development cooperation (CRPD Article 32), the Committee notes that the mainstreaming of disability is not fully applied (ibid., p. 17). Such examples show that, despite the CRPD, the *Humanitarian Charter*, and the *IASC Guidelines*, the old perception of 'vulnerability and dependence'—instead of persons with disabilities as active agents—has not been fully overcome.

Fostering an understanding of persons with disabilities as passive recipients of aid bears the risk of supporting measures, which are limited to assistance-based activities rather than those that enhance their capacities, participation, and empowerment (e.g., GFFO, 2019). As indicated, the German Humanitarian Strategy underlines that affected populations should be treated as active agents rather than passive recipients of assistance (GFFO, 2019, 10). It would be useful if the OECD-DAC evaluated the actual progress in *translation* and *implementation* of its member states, so that the lack of consistent implementation and evaluations can be addressed.

Donor policies set the stage for the interorganizational and organizational translation of the disability inclusion norm cluster. With the *IASC Guidelines*, much work on disability inclusion has been accomplished at the interorganizational level, particularly with the four "must-do" actions. However, there is still more to be done. The translation into guidelines and standards does not mean that individual organizations have the expertise or resources to implement the disability norm cluster. For example, collecting better gender, age, and disability disaggregated data only matters, when it successfully informs programs, projects, and advocacy. Just as with the policies at the donor level, sufficient funding, clear objectives, disability markers, deliverables, timelines, regular evaluations, knowledge sharing of good practices and lessons learned, and supporting research to enhance the evidence base are all necessary at the level of the individual organization.

With the shift from norm institutionalization to translation the number of actors increases rapidly. This chapter has studied norm translation in three steps. It first looked at donor policies, then at the interorganizational level, and finally at individual organizations. The least information is available on the individual organizations. Humanitarian organizations differ widely in their attention to disability inclusion, and they do not have a standardized way of reporting and providing other information on disability inclusion. As a result, it is very challenging to judge the quality of their inclusion work. In general, all actors should provide more specific information on disability inclusion. Yet, it is clear that norm robustness is more limited during translation than during institutionalization. The next chapter will study norm implementation in Cox's Bazar, Bangladesh and South Sudan.

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CHAPTER 5

Implementing Disability Inclusion: Comparing Bangladesh and South Sudan

Abstract This chapter comparatively examines the implementation of disability inclusion in two humanitarian crises, Cox's Bazar, Bangladesh and South Sudan. These divergent cases illustrate in different ways the challenges and opportunities for implementing disability inclusion in complex and protracted emergencies. It shows that many organizations know about the CRPD and recognize the need to become disability-inclusive. However, most struggle with the implementation of the disability inclusion norm cluster. This chapter elucidates the reasons for incomplete implementation and limited impact of disability inclusion.

Keywords Norm implementation · Protracted emergencies · Humanitarian crises · Limited impact · Bangladesh · South Sudan

5.1 Introduction

The previous chapters have shown that the types of actors involved in translation of a norm cluster is broader than in institutionalization. With implementation at the country level, the number and types of actors multiplies further, as local, national, and international actors come together. We selected humanitarian crises in Bangladesh and South Sudan

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as case studies, because together they show a wide variety of norm development issues (see Sect. 2.6). The first is a humanitarian crisis in a comparatively small area, Cox's Bazar, which is home to the world's largest compound of refugee camps. The other is located amidst a nationwide civil war, with several armed factions, malnutrition, frequently bordering on famine, leading to forced migration: internally displaced persons in South Sudan and refugees in neighboring countries. These divergent cases illustrate in different ways the challenges and opportunities in implementing disability inclusion in complex and protracted emergencies. In Cox's Bazar, eight UN agencies work with 134 operational partners, including both national and international NGOs (ISCG, 2020, 2021). In South Sudan, ten UN agencies have a representation and work with 173 partners (107 national NGOs and 66 international NGOs) (OCHA, 2022, 25). Our research shows that many organizations know about the CRPD and recognize the need to become disability-inclusive. However, many organizations struggle to implement the "must-do" actions. To understand the slow implementation of the disability inclusion norm cluster, a closer look at their practices is necessary.

5.2 The Rohingya Refugee Crisis

The *Rohingya refugee crisis* is the main humanitarian challenge in the Asia–Pacific region (Mixed Migration Centre, 2019, 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 (OCHA, n.d.). They now reside in 34 extremely congested camps, located in the two *upazilas* (administrative areas) of Teknaf and Ukhiya (ISCG, 2020, 13). The situation in the camps is precarious and the vast majority of the refugees remains entirely dependent on humanitarian action (UNHCR and REACH Initiative, 2019, 5). The Rohingya influx has also put an enormous burden on the host communities that now compete for scarce resources with the refugees (ISCG, 2020, 29–31).

Officially, Bangladesh attaches great importance to the inclusion of persons with disabilities. It was one of the first countries to sign the CRPD and its Optional Protocol, and in 2013, it passed a national policy—the *Rights and Protection of Persons with Disabilities Act*. In principle, it thus 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. Various

accountability mechanisms at different administrative levels oversee the implementation of the act and strive to protect the rights of persons with disabilities. However, persons with disabilities still face many barriers that prevent them from fully enjoying their human rights. The availability of data is poor due to the lack of officially published national statistics on persons with disabilities, and only a few comprehensive needs assessments of the Bangladeshi population have been carried out by humanitarian actors.[1] Moreover, while employees of local government institutions are working to become more inclusive, they often lack awareness and knowledge about the rights of persons with disabilities and international and national protection standards.[2] As in many developing economies, roads and infrastructure in Cox's Bazar and many other regions in Bangladesh 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 (Funke & Dijkzeul, 2021b, 41). In host communities, persons with disabilities also face discrimination and many people still perceive them as "passive victims", who lack any sense of agency (Funke & Dijkzeul, 2021b, 41).

For refugees with disabilities, the situation is even more dire than for those in the host communities (Funke & Dijkzeul, 2021b, 35). The Government of Bangladesh officially considers the crisis as a short-term challenge and, as stated, refers to the Rohingya as "forcibly displaced Myanmar nationals", rather than refugees (Funke & Dijkzeul, 2021b, 35). It therefore does not follow international refugee law. This failure to apply international refugee law norms means that the Government of Bangladesh prevents the Rohingyas from forming themselves into organizations, restricts the freedom of movement through the construction of fencing around the hilly Rohingya camps, and has forcibly displaced thousands of Rohingyas to Bashan Char, a low-lying island in the Gulf of Bengal that is prone to flooding. Further, by not applying international refugee law the Government of Bangladesh can officially prevent

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

[2] Several international organizations and scholars also raise the issue of corruption (bdnews24.com, 2019; Risk and Compliance Portal, 2020).

the Rohingyas from working. In this context, human rights advocates and numerous international NGOs have raised strong concerns in a joint statement about the obstacles that Rohingya refugees experience in exercising their fundamental rights and freedoms, including their rights to education, livelihoods, and full integration into the host communities.[3] These restrictions only compounded the existing challenges and risks for Rohingya refugees with disabilities who face additional discrimination, stigma, and exclusion placing them in further vulnerable and dangerous situations.

In the camps, persons with disabilities face numerous barriers that prevent them from accessing crucial services and meaningfully claiming their rights. 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 (Funke & Dijkzeul, 2021b, 35). These facilities are either located far away, uphill, across difficult terrain, or are constructed in such a way that they are difficult to access or operate for persons with disabilities (Funke & Dijkzeul, 2021b, 35). 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 (Funke & Dijkzeul, 2021b, 36). Regrettably, these barriers are extremely difficult to reduce once they have been established. The overcrowding of the camps limits the available space for an expansion or remodeling of existing facilities. Moreover, discrimination and negative attitudes toward persons with disabilities within the communities mean that persons with disabilities rarely leave their makeshift shelters and then become "invisible" in the camps. If they do leave their shelter and have a visible impairment, they face increased stigma (Funke & Dijkzeul, 2021b).

In short, the Government of Bangladesh may officially respect the disability inclusion norm in its domestic policies, but it does not respect

[3] Twenty-seven organizations signed the statement, including CARE, Danish Refugee Council, HI, Norwegian Refugee Council, and World Vision (see Human Rights Watch, 2019; Amnesty International 2020; InterAction, International Council of Voluntary Agencies, 2020).

the norms of international refugee law.[4] As a result, the disability inclusion norm cluster is barely being implemented, and humanitarian organizations struggle to uphold international refugee law, the CRPD, and the *IASC Guidelines*, despite great needs. Meaningful participation, the removal of barriers, empowerment, and the collection of reliable data are limited. In Cox's Bazar, humanitarian actors require considerable resources to address past failures in the planning and construction of the camps' infrastructure. To make services accessible for everyone, roads, facilities, and shelters must be remodeled. Yet short funding cycles, frequent staff turnover, and administrative procedures required by the national authorities that entail a high workload for humanitarian staff (e.g., for obtaining visa, accreditation, and working permits) reduce the time and resources available to create an inclusive environment and ensure the meaningful participation of persons with disabilities. These issues also take away time that could be spent on building the capacity of humanitarian staff.

Finally, many humanitarian organizations in Bangladesh have only just started to build their capacity and thus lack expertise on how to ensure the inclusion of persons with disabilities in their programs. Despite a growing level of commitment from the humanitarian actors, as evidenced through their signing of the *Humanitarian Disability Charter*, a systematic approach to ensuring the inclusion of persons with disabilities in their organizations, programs, and services is still lacking. In fact, the inclusion of persons with disabilities most often depends on the initiatives of a few individuals within the organizations. Moreover, there are still insufficient donor resources allocated to inclusive humanitarian action.

5.3 The South Sudanese Civil War

In *South Sudan*, persons with disabilities face similar barriers in their daily lives. Here, it is not so much that the government explicitly does not want to respect International Law concerning forced displacement, but

[4] Legal experts will make the case that the Bangladeshi government is still bound by the obligations of Article 11 as well as the CRPD generally. With essential control over the Rohingyas in its territory, experts argue, it does not matter that the government does not apply refugee law. It still has CRPD obligations to the persons with disabilities in its territory. The fact that the Government of Bangladesh neither respects the obligations from the CRPD nor refugee law for the Rohingyas also illustrates that norm institutionalization can differ considerably from norm translation and implementation.

more a case of overall state failure, corruption, and violence (Funke & Dijkzeul, 2021a, 63). A civil war has been raging since 2013 and the weak government barely provides social services.

Unlike Bangladesh, South Sudan has only recently signed and ratified the CRPD. However, South Sudan was already officially bound to grant its citizens the same rights and entitlements as Sudan, which has ratified the CRPD and its Optional Protocol in 2009, 2 years before independence (OHCHR, 2018). The fighting and the deliberate obstruction of the reconstitution of the parliament by the ruling party—in contradiction to the 2018 peace deal—stalled legislative processes for a long time (Voice of America, 2021). In the end, South Sudanese civil society, including the national disability movement, used the signing of the CRPD in February 2023 to advocate for disability rights. It then successfully advocated for ratification.

The Transitional Constitution of the Republic of South Sudan of 2011 has several articles relevant for persons with disabilities. Article 6, for example, promotes the development of a sign language. Nevertheless, the Transitional Constitution takes a welfare approach to disability and only indirectly refers to persons with disabilities as part of a larger group of "persons with special needs" (Government of Southern Sudan, 2011). It officially grants this group full participation in society and enjoyment of rights and freedoms as well as "the right to the respect of their dignity" (Article 30). Yet, the Transitional Constitution fails to define who precisely belongs to the group of "persons with special needs".

Interestingly, South Sudan's policies relevant for the protection of the human rights of persons with disabilities are more advanced than its legislation. In 2014, the Ministry of Education, Science and Technology with support from the international inclusion-focused NGO Light for the World issued a policy position paper on a National Inclusive Education Policy (South Sudan, Ministry of Education, Science and Technology, 2014). The position paper provides a vision for inclusive education and seeks to ensure that all children are given the opportunity to reach their potential. The Ministry adopted the policy in 2021.

Six years earlier, the Ministry of Gender, Child Welfare, Humanitarian Affairs and Disaster Management had already passed a *National Disability and Inclusion Policy*, hence meeting one of the objectives of the 2011 South Sudan Development Plan (South Sudan, Ministry of Gender, Child, Social Welfare, Humanitarian Affairs and Disaster Management,

2013). Unlike the Transitional Constitution, the *Disability and Inclusion Policy* reflects a human rights-based understanding of disability and pursues a two-fold goal: (1) address and respond to the vulnerabilities of persons with disabilities; and (2) promote and protect their rights and dignity in an inclusive manner. Yet, as in many developing countries with weak state structures, implementation of these policies lags and persons with disabilities continue to face attitudinal, environmental, and institutional barriers that prevent them from fully participating in society and meeting their needs (Funke & Dijkzeul, 2021a, 25).

Generally, but also specifically in the context of the civil war, persons with physical impairments have difficulties using services and participating in livelihood opportunities because they have barely any access to assistive devices that would enable them to reach service points and meaningfully engage in community life. Some of them make their own devices from the material they can buy on the market or find on the streets, but these cannot replace professional support equipment, such as crutches, wheelchairs, and hearing aids (Focus group discussions Yambio and Yei, May/June 2021).

Moreover, persons with disabilities encounter discrimination in the job market and lack job opportunities either because they are often prevented from pursuing an education that would give them the necessary skills and qualifications to compete with other potential employees or because employers regard them as "incomplete" or incapable of working (Funke & Dijkzeul, 2021a, 22). Only a very small number of them find employment in OPDs or inclusion-focused organizations. Some persons with disabilities do volunteer work, but hardly ever can they engage in any income-generating activities that would help them to sustain their families or contribute to their household income. Consequently, they also have more difficulties in securing loans or support from financial institutions and legal services (Focus group discussions Yambio and Yei, May/June 2021).

In addition, inaccessible buildings and the lack of public transport possibilities and a poor road network prevent many persons with a physical impairment to reach service points or health and education facilities, which are often located far from the community (Focus group discussions Yambio and Yei, May/June 2021). Frequent flooding in the rainy seasons also hampers access. Moreover, persons with a visual impairment usually do not receive the necessary assistance to locate services and service points. Where they can access these facilities, they may

encounter negative attitudes by the service providers, discrimination, and even harassment (Handicap International, 2017, 4). Barriers and facilitator assessments in the health sector found that attitudes among health personnel varied according to the type of disability; persons with physical impairments faced less discrimination than persons with hearing or intellectual impairments (Handicap International 2017, 4).

In South Sudan, humanitarian organizations now invest in capacity building and awareness raising during the response. Thanks to these efforts, the first tangible progress is becoming visible. Humanitarian actors increasingly incorporate the Washington Group Short Set on Functioning into their monitoring and evaluation tools, recruit persons with disabilities, support the establishment OPDs, and make distribution points and service facilities more accessible. However, South Sudan is a large country with little infrastructure and many remote areas are not reached, especially during the rainy season. Serious gaps and challenges to disability inclusion remain. Most humanitarian organizations still fail to recognize the diversity of disability and lack strategies to include persons with intellectual and psychosocial impairments (Funke, 2022, 389). Moreover, persons with disabilities rarely participate in the project design phase and seldom contribute to program development. Furthermore, there is no nation-wide approach for the collection, analysis, and use of disability disaggregated data, resulting in important information gaps on ongoing needs and barriers to inclusion in the needs assessments. In addition, communication barriers and lack of reasonable accommodation in consultation meetings hinder the effective participation of persons with hearing, visual, and other types of disabilities and make them dependent on family members and other caregivers (Funke, 2022, 390–391).

Although humanitarian actors currently face somewhat better conditions to implement the four "must-do" actions in South Sudan than in Bangladesh, prejudices and lack of expertise in disability inclusion in the humanitarian community, as well as government neglect, are hard to address in the short term.

5.4 Comparative Analysis of the Slow Implementation of Norms on the Ground

The cases of Cox's Bazar, Bangladesh and South Sudan illustrate the challenges of slow implementation, and hence limited compliance with the disability inclusion norm cluster. It is revealing that in these two very dissimilar cases, the challenges persons with disabilities face are very similar. The barriers and risks they encounter are comparable, regardless of either government structure or whether the government is dealing with a refugee situation in a specific region or a nation-wide civil war. Progress in policy development to strengthen the disability inclusion norm cluster at the international, national, and interorganizational (strategic) levels does not have a tangible effect on the "norm targets", and hence, the protection and inclusion of persons with disabilities "on the ground" (Funke & Dijkzeul, 2021b, 4). Put differently, improvements in institutionalization and translation do not necessarily lead to improved implementation. Four main reasons account for the slow implementation of the disability inclusion norm cluster: (1) norm evasion by the central authorities; (2) lack of skills, confidence, and capacity of the humanitarian organizations involved; (3) donor requirements and conditionalities; and (4) the difficult operational environments.

In Bangladesh, the government has ratified the CRPD and the Optional Protocol but does not adhere to its legal obligations toward the Rohingyas. As mentioned, it rejects explicitly its obligations under international refugee law and implicitly the CRPD; it does not grant refugees with disabilities the same rights and entitlements as its own citizens. In concrete terms, this means that Rohingyas are not allowed to organize themselves and form OPDs, engage in employment and livelihood activities, and receive formal education. Thus, in the context of Bangladesh, the two legal regimes, the CRPD and the 1951 Refugee Convention, which are supposed to complement each other, are not applied well enough. This hinders humanitarian organizations from creating a more favorable and inclusive environment for persons with disabilities in the refugee camps.

In South Sudan, progress in the protection and inclusion of persons with disabilities has been extremely limited because the government was, as indicated above, very slow with signing and ratifying the CRPD, and it still has not signed the Optional Protocol. Simultaneously, the implementation of its Inclusion Policy and Inclusive Education Policies and

other relevant commitments toward persons with disabilities are lagging due to the civil war, internal power struggles in the ruling coalition, and the failure to implement the Peace Accords (Funke, 2022, 395). While the government does not oppose the disability inclusion norm cluster, it does not prioritize its implementation in practice either. Thus, we cannot speak of norm rejection but rather of *norm evasion*, which necessitates humanitarian organizations to step in and do their best to protect and assist persons with disabilities.

Both cases show that humanitarian organizations have or are in the process of developing policies, strategies, or guidelines to make their services inclusive and accessible even in situations of norm evasion. However, their employees often lack the skills, confidence, and capacity to implement the four "must-do" actions of the disability inclusion norm cluster. As mentioned, they often do not know how to overcome communication barriers, meaningfully integrate the Washington Group Short Set on Functioning into their surveys, remodel their service points and utilities, and involve persons with disabilities and OPDs in their operations. Compounding the problem is that donors traditionally do not have dedicated funding for capacity building because they often see it as part of development work rather than humanitarian action (Funke & Dijkzeul, 2021b).

Overall, the case studies illustrate that neither the authorities nor humanitarians and donors reject the disability inclusion norm cluster. Yet, patchy and slow implementation challenges the norm cluster's robustness. Whereas donors and humanitarian organizations have begun to invest into capacity building to enhance skills and confidence in inclusive humanitarian action, national authorities still need to create a favorable environment for inclusion, where complementing legal regimes are not played out against each other, persons with disabilities can organize themselves, and all actors are held accountable for norm violations, evasion, and non-compliance.

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CHAPTER 6

Analysis Across Actors and Levels

Abstract This chapter analyzes the key findings using the theoretical framework we developed in Chapter 2. Importantly, we highlight important differences among the levels of global governance and show the shortcomings of norm robustness as a concept for the study of norm translation and implementation. The robustness of a norm cluster cannot be explained well by contestation, deliberate norm violation, or intended non-compliance. Rather, other policy priorities and lack of capacities account for the lack of implementation and the relatively low impact of inclusion in the lives of persons with disabilities. We call this norm evasion. The multi-level approach implies a sea change in the study of International Law and IR, which need to leave their traditional confines behind. They should extend their reach and use more multi-method research to study all governance levels, as well as the interaction among them. In the final section, we also provide recommendations on how to address diversity in humanitarian action.

Keywords Global governance · Levels of analysis · Norm robustness · International relations · International Law

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6.1 Introduction

The complex nature of international norms implies that *institutionalization*, *translation*, and *implementation* move at different speeds in which some elements of a cluster receive more attention than others (Funke, 2022a, 223). Yet, a narrow focus on states neglects the impact of norms on other addressees, such as international organizations and, of course, persons with disabilities themselves and their OPDs. After an analysis of the main mechanisms of norm development across actors and levels, this chapter presents courses of action to strengthen the disability inclusion norm cluster's robustness.

6.2 Variation in Institutionalization, Translation, and Implementation

At the international level, the CRPD has over time *institutionalized* an understanding of disability as a human rights issue. It resulted in the translation of its core principles into soft law to which non-state actors could also subscribe. The soft-law instruments also offered the possibility for donor states, in particular the United States, to accept disability inclusion at the international level, yet without acceding to the CRPD. Paradoxically, the soft norm-setting efforts for humanitarian action only followed once the hard law—the CRPD with its distinct Article 11—had already been established, and not the other way around.

A few donors, in particular Finland and the European Union, now play a crucial role as so-called "norm entrepreneurs" to further promote the consistent inclusion of persons with disabilities into policy and practice through three discrete means: (1) financial and other incentives, (2) persuasion, and (3) socialization (Finnemore & Hollis, 2016, 449). The large and increasing number of ratifications of the CRPD as well as the numerous signatories of the *Humanitarian Disability Charter* also indicate a growing acceptance of disability inclusion as a human rights issue at the international level.

Yet, the precise impact of donor policies and the way they promote the inclusion of persons with disabilities at other levels of global governance is often hard to determine, especially because most policies remain abstract and do not contain specific operational requirements. Moreover, donors rely on *translation* and *implementation* by their partners, UN organizations and NGOs. Countries like the United Kingdom and

Australia with their detailed and transparent strategies, including concise timelines, markers, requirements, and deliverables, have lost influence as norm entrepreneurs due to significant budget cuts and—in the case of Australia—absence of a follow-up strategy. Without sustainable funding and a strategic vision, implementation of inclusive humanitarian action will become harder for their partners. Consequently, we indeed must think of "norm robustness" in broader terms than the state-based ratification, accession, or formal commitment to a norm and explore how norms shape and are shaped by practices and interactions at various levels of governance, in particular their implementation on the "ground" (Betts & Orchard, 2014, 1).

Looking at disability inclusion in humanitarian action, such as broader approach also requires further specification of the various levels of governance. Current studies commonly refer to two or three levels of norm development (see Table 2.1). This book shows that it is more precise to further disaggregate these levels in an actor-focused manner. This helps, for example, to distinguish between donor governments and recipient governments at the national level, and not just between governments and implementing organizations (Table 6.1).

Concerning *translation* at the national donor government level,[1] evaluations that measure the effects of donor requirements, for example, regarding the collection and use of gender, age, and disability disaggregated data, would particularly provide a better understanding of the norm cluster's robustness. At present, however, such evaluations are missing. Even without such information, it is obvious that humanitarian organizations depend on reliable and flexible funding to mainstream disability into their humanitarian operations (Funke & Dijkzeul, 2021, 15). Donor policies without sufficient and sustainable funding, clear timelines, requirements, markers, and deliverables for disability inclusion bear the risk to further delay the protection and assistance of persons with disabilities on the ground. To strengthen the robustness of the disability inclusion norm cluster, more donors must start translating their commitments into concrete and coherent strategies, tools, and funding requirements. In general, donors and other actors are still struggling with human diversity with regard to translation and implementation. Norm theory needs to pay closer attention to this.

[1] Including the European Union, which is not a national donor government but a major humanitarian donor and party to the CRPD.

Table 6.1 Closer specification of levels, mechanisms, actors, and outcomes

Levels of global governance	*Main mechanism of norm development*	*Main actors/Norm addressees*	*Desired outcomes*
International Level	Institutionalization	States in intergovernmental organizations (e.g., UN System) and coordination bodies	Conventions, resolutions, international standards, guidelines; treaty ratification / accession
National Level Donor Government	Translation into international donor policy	Government bureaucracy, humanitarian organizations, and broader civil society	Domestic law and/ or thematic policies, humanitarian donor strategy/policy, funding policies/ decisions
National Level Recipient Government	Translation into domestic policy and law	National government, sub-national authorities	Domestic law, accreditation, humanitarian strategy/policy
Interorganizational (Strategic) Level	Translation into organizational strategy and policies	Strategic management of humanitarian organizations	Organizational policy and capacity building
Local Level	Implementation	Humanitarian organizations at country / field level, target groups and other actors in the humanitarian arena	Access to assistance and protection for people of concern/ target groups

For translation at the organizational level, humanitarian organizations, in turn, need to enhance organizational learning and adapt their work procedures to ensure that their services are accessible to persons with disabilities. Since the publication of the *IASC Guidelines*, we observe a nascent effort toward more systematic translation of the disability inclusion norm cluster across the humanitarian system. But public information is lacking. At the moment, the United Nations with its elaborate *Disability Inclusion Strategy* and mandatory reporting mechanism for every UN entity is making the most visible progress with respect to all four "must-do" actions. This is remarkable since the *IASC Guidelines* and the *UN Disability Inclusion Strategy* have only been launched in 2019, although the process to a more disability-inclusive humanitarian system already

started a few years earlier when the 2016 World Humanitarian Summit initiated rapid soft-law development on disability inclusion in humanitarian action. The UK Foreign Commonwealth Development Office's (then still called DFID) funding has provided a crucial impetus here.

Examining *implementation* at the domestic level in recipient countries, it becomes clearer that other issue areas compete for attention, and that some actors follow their own interests, or simply ignore the problem. The Bangladeshi government does not accept the Rohingya as refugees and does not respect international refugee law. It essentially rejects their local integration. The South Sudanese government barely functions. It has left the provision of basic services to the international community. The fact that norms are not well translated or implemented can thus better be explained by both the lack of interest and low capacities of the national governments, than by challenges over the meaning of the norms or the norm cluster. This contrasts with the international level, where—the possibilities of—more contentious debates play a central role in *institutionalization*.

At the local or field level, humanitarian organizations invest increasingly in their own capacity building and some establish partnerships with inclusion-focused NGOs to build expertise (Funke, 2022b, 388). But the implementation of the inclusion norm cluster does not follow a linear path and often still depends on the efforts of dedicated individuals. Inclusion has still not established itself as a cross-cutting issue in all programs and organizations.

Interestingly, the robustness of the disability inclusion norm cluster or the lack thereof during *implementation* cannot be explained by *contestation* (Wiener, 2014), deliberate norm *violation* or explicitly intended *non-compliance* (Panke & Petersohn, 2012), as it is commonly argued in IR norm research. Rather, other policy priorities as in the case of Bangladesh, or lack of capacities in South Sudan, explain the lack of implementation. Hence, the two very different countries both give a low priority to translating complex normative obligations of disability inclusion into concrete policy steps. In other words, with the logic of action of the CRPD and the *IASC Guidelines*, errors of omission explain slow norm implementation better than theories of deliberate contestation, violation, and willful non-compliance. We coin this process as *norm evasion*, which needs to be added to the lists of concepts that explains (limited) norm robustness. Empirically, in contrast with norm contestation, violation, and compliance, which are usually applied at the institutional level, norm

evasion applies particularly to the field level. One of the reasons is that normative obligations, as in the case of the CRPD in complex norm clusters, never come with clear priorities, resources, or a ready-made handbook on how to prepare the ground for their implementation.

In sum, explaining variation in *institutionalization, translation, and implementation*, and how this affects the robustness of the norms or norm clusters in question requires substantial research at all levels of global governance. Explaining what works at one level of global governance may require concepts, such as *norm contestation* at the international level, that do not work well at other levels of global governance.

6.3 Strengthening Disability Inclusion in Crises: Linking and Integrating Humanitarian Action and Development

So far, this book has shown that although many organizations have made some progress toward translating inclusion, a considerable amount of work is still necessary before they will be able to fully implement the disability inclusion norm cluster. The following recommendations will help in this respect. Ultimately, improvements in the lives of persons with disabilities determine whether the inclusion norm cluster and concomitant policies have been successful. Hence, this section indicates and discusses recommendations for the various levels of global governance that can contribute to further improvements.[2]

6.3.1 All Actors

- All actors should utilize and integrate the *IASC Guidelines* into their policies and processes in responding to humanitarian crises. This implies implementing the four "must-do" actions of (1) promoting meaningful participation; (2) removing barriers; (3) empowering persons with disabilities and supporting their capacity development; and (4) disaggregating data for monitoring inclusion, using the Washington Group Questions where possible, and paying attention

[2] These recommendations complement Chapter 9 of the *IASC Guidelines*, which explains the different roles and responsibilities of humanitarian actors and other stakeholders.

to the roles and responsibilities of different stakeholders throughout the humanitarian program cycle.[3]

6.3.2 *International Level: States in Intergovernmental Organizations*

- Encourage all UN member states to ratify or accede to the CRPD and its Optional Protocol, especially those that are traditionally reluctant to become party to international Conventions.
- Make the CRPD and its Optional Protocol accessible through translations into local languages, including easy-to-read versions and sign language.
- Contribute to discussions of the Committee on the Rights of Persons with Disabilities and advocate for a regular exchange on Article 11 on persons with disabilities in situations of risk and humanitarian emergencies.
- Organize side events and other opportunities for exchange during meetings of the Conference of States Parties to the CRPD to strengthen institutionalization, translation, and implementation.
- Support the work of the Special Rapporteur on the rights of persons with disabilities in the context of situations of risk, including armed conflict, humanitarian emergencies, and natural disasters.
- Continue monitoring disability inclusion throughout the humanitarian programming cycle.

6.3.3 *National Level—Donor Governments*

- Design humanitarian policies with a disability focus and include an accountability mechanism. Ensure that persons with disabilities and their representative organizations can meaningfully participate in this process. Ensure that they represent the diversity of persons with disabilities.

[3] The humanitarian program cycle is the joint humanitarian programming process at the country level led by OCHA. This process includes the Multi-sector Initial Rapid Assessments immediately after a disaster. In somewhat more chronic crises, it includes the Humanitarian Needs Overviews and Humanitarian Response Plans, as well as impact assessments and other evaluations.

- Establish accessible information management systems and carry out evaluations, not just of institutionalization, but also of translation and especially implementation.
- Encourage and enable staff of donor agencies to regularly participate in trainings on disability inclusion, for example on "Introduction to disability-inclusive humanitarian action" developed by the Global Reference Group on Inclusion of Persons with Disabilities in Humanitarian Action, or the course of the UN System Staff College.
- Establish a dedicated disability inclusion focal point for humanitarian action and disaster risk reduction for implementing partners in the responsible ministries and/or departments.
- Provide sustainable and reliable funding for implementing partners, especially OPDs. This is also becoming more important as many crises are becoming increasingly protracted.
- Support international organizations, recipient governments, humanitarian NGOs, and OPDs with implementing these recommendations. Policies with clear timelines and deliverables help in this respect.

6.3.4 National Level—Recipient Governments

- In line with the CRPD and the Humanitarian Disability Charter, design national laws and policies with a disability focus and include accountability mechanisms.
- Ensure that persons with disabilities and their representative organizations can meaningfully participate in this lawmaking and policy formulation process. Ensure that they represent the diversity of persons with disabilities.
- Regularly review and/or establish accessible government services.
- Establish accessible information management systems on disability inclusion.
- Enable national authorities who coordinate with humanitarian partners to participate in regular training courses on disability inclusion.
- Ensure that national household surveys, Humanitarian Needs Overviews, and national censuses incorporate the Washington Group Short Set on Functioning to generate more reliable data on disability.

- Establish a dedicated disability inclusion focal point to promote and monitor inclusion.
- Support the founding and functioning of OPDs.

6.3.5 Interorganizational Level: Strategic Management of Humanitarian Organizations

- Design inclusion policies with clear indicators and accountability mechanisms.
- Establish accessible information management systems, accountability mechanisms, and monitoring tools.
- Systematically evaluate and report on disability.
- Include disability in results frameworks and response plans.
- Invest in capacity building of staff at all levels of the humanitarian response.
- Contribute to the revision of *Sphere* and the *Core Humanitarian Standard* regarding inclusion.
- Establish a dedicated disability focal point to monitor inclusion and support country and field teams.
- Ensure sufficient resources are allocated to reasonable accommodations and facilities for persons with disabilities.
- Organize side events and other opportunities for exchange among States Parties, UN organizations, NGOs, OPDs, and persons with disabilities during meetings of the Conference of States Parties to the CRPD.
- Engage in joint evaluations to assess the degree of progress with disability inclusion.

6.3.6 Local Level: Humanitarian Organizations at Country or Field Level

- Implement the four "must-do" actions throughout the humanitarian program cycle in line with the *IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action*.
- Invest in capacity building of staff, including dedicated focal points on disability inclusion in the cluster system.
- Hire and work with persons with disabilities.

- Monitor and evaluate disability inclusion in order to better understand implementation processes and impact.
- Think through and ensure follow-up actions to gender, age, and disability disaggregated data.

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CHAPTER 7

Conclusions

Abstract The concluding chapter summarizes the findings and discusses the shortcomings of current International Law and IR norm theory. It highlights the need for a multi-level perspective for studying norm robustness. Furthermore, it highlights the need to integrate a multi-level, mixed method approach to norms on diversity and inclusion to understand the impact of norms at the various levels of global governance. The final section stresses the importance for more comparative research with other, sometimes overlapping norm clusters (e.g., on gender, racism, LGBTQI+, or older persons) to deepen our insight on norm development and impact, as well as about the interaction of governmental and non-governmental action at various levels.

Keywords Norm clusters · Impact · Multi-level perspective · Human diversity · Inclusion · Global governance

7.1 Introduction

This book examined how the disability inclusion norm cluster maintains, strengthens, or loosens its robustness during processes of institutionalization, translation, and implementation. It applied a multi-level Sociology

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of Law approach to better understand the development of disability inclusion in humanitarian crises and the impact of the norm cluster "on the ground".

7.2 Disability

International Law and humanitarian action struggle to reflect and incorporate human diversity, including the rights of persons with disabilities. Over the years, International Law and policy have changed more than actual practice. The CRPD was an important step forward but needed the 2016 World Humanitarian Summit and its Humanitarian Disability Charter to strengthen policy attention to inclusion. This in turn led to the formulation of the 2019 *IASC Guidelines* and a host of other soft-law documents. The *IASC Guidelines* refer to the CRPD and strengthen disability inclusion as a human rights issue in humanitarian action, in particular with its four "must-do" actions.

Hence, a broad and increasingly institutionalized consensus now exists among donors and the humanitarian community that persons with disabilities are not passive subjects of charity but should be—and usually are—able to make an active contribution to the humanitarian response, although many public officials, international organizations, scholars, and persons with disabilities agree that stronger efforts are required to design, implement, and monitor inclusive humanitarian programs. This also means that the human rights model of disability is increasingly prevailing over other disability models, but the older models still linger on in traditional mindsets and incomplete or vague policies and implementation.

In line with the *IASC Guidelines*, this book shows that whereas the four "must-do" actions serve as a useful reference point for humanitarian programming, context-specific guidance and capacity development are often needed. Gaps in their implementation weaken the robustness of rights-based inclusion. Inclusion-focused organizations, such as HI, CBM, and Light for the World, play a crucial role in this regard because they often have more expertise and experience in inclusive humanitarian action than mainstream actors.

The four "must-do" actions are the component norms of the norm cluster of inclusive humanitarian action. Humanitarian actors struggle with the fact that these actions are interconnected. In practice, this means that in order to address persisting barriers, it is crucial to have solid data, empower persons with disabilities, and meaningfully engage them in

the humanitarian response. Simultaneously, their meaningful participation depends on the removal of attitudinal, environmental, and institutional barriers, their familiarity with their rights and their abilities to make claims about their needs, as well as the availability of disaggregated data. Although the four "must-do" actions help to organize inclusive action across all levels of global governance, many donor governments, humanitarian organizations, and the humanitarian country teams still lack concrete strategies that (fully) reflect the "must-do" actions. Yet, such translation into policies, tools, and indicators is a prerequisite for broadening the collective of included people and successful implementation in the field. Humanitarian organizations face the dilemma that on the one hand they need to link the four component norms to enhance effectiveness. On the other, they lack resources and must set priorities. This underscores the important role of donors in promoting disability inclusion "on the ground". However, most donors are only at the early stages of translating the disability inclusion norm cluster into their policies and must provide more funding. The declining leadership roles of the United Kingdom and Australia in disability inclusion serves as an uncomfortable reminder that achieving disability-inclusive humanitarian action requires consistent determination and prioritization.

7.3 Norm Theory

Theoretically, norms are central to IR, but the three main schools generally lack an understanding of how norms influence practice. Neo-realists are right to point out that norms function only slowly or imperfectly and that state power is crucial, but they are wrong to deny their relevance. All three schools woefully lack in their understanding of translation and implementation, because they traditionally focus more on states and international organizations than other actors and therefore fail to see empirically and theoretically what happens at other levels of global governance. Ironically, just like many of their International Law colleagues, IR scholars then often remain stuck in the normative realm, which limits their ability to discern—the lack of—changes in practice.

Currently, more specific norm theory highlights the composite and complex character of many norms. The idea that international norms tend "to be clustered, nested and 'composite' in character" (Betts & Orchard, 2014, 10) is not new to IR norm research and International Law, but this study shows that studying the evolution of norms requires further

theoretical and empirical refinement. Although norm cluster scholarship recognizes the "inherently dynamic character" of norms and their continuous evolution (Finnemore & Hollis, 2016, 428), IR and legal scholars pay too little attention to the conceptual structure of the norm(s) in question, their relationship to other (component) norms or principles in other issue areas, and their development and often incomplete impact across levels of global governance. The concept of "norm clusters" represents a useful vantage point to describe and analyze various degrees and forms of norm development in specific humanitarian contexts. The more component norms a norm cluster has, the more difficult it will become to speak about norm robustness, because the component norms are often institutionalized, translated, and implemented at different speeds. Institutionalization may look impressive for soft law or policies at the international level, but translation into domestic or organizational policies and implementation on the ground generally lag behind.

The concept of robustness of norms is too generic to sufficiently account for the dynamic and composite character of human rights norm clusters at these different governance levels. Moreover, within norm clusters robustness also varies for each component norm because the implementation "on the ground" is challenging and actors may choose to implement only selected (sets of) component norms instead of the whole cluster. The cases of disability inclusion show that even when norm clusters enjoy international commitment and dedicated support, their translation and implementation varies considerably across geographical areas, donors, and humanitarian organizations, as well as the component norms themselves. In sum, "norm robustness" may at first seem more strongly institutionalized at the global and then (partly) translated into policies of different actors, but it almost invariably looks more disappointing when analyzing actual implementation at the organizational or local levels.

Both International Law and IR, traditionally state-centered disciplines, devote most attention to norm institutionalization among states at the international level. They often fail to see both the actual suffering and agency of persons with disabilities. Admittedly, the breadth of component norms and the number of actors involved make multi-level research quite demanding and time-consuming. Still, International Law and Human Rights more specifically, do not exist in a vacuum; in humanitarian crises, different types of actors interpret, use, and implement a variety of norms, while others neglect or purposefully violate them. In doing

so, these actors contribute to either norm strengthening, weakening, or erosion. Also in this respect, we must move beyond both traditional legal analysis and international policy analysis, to better understand the structures and interpretation of the norm clusters, and how this relates to their robustness at different levels of governance. This conclusion affirms recent research by Price and Sikkink that shows that institutionalizing norms in International Law and institutions does not guarantee changes in behavior. Yet, International Law can contribute to behavioral change over time (Price and Sikkink, 2021, 47). As stated, studying the practices of states and non-state actors at different levels of global governance explains more about the (lack of) robustness of a norm cluster than actual ratification of accession to a treaty.

Our analysis from a Sociology of Law perspective suggests that at the national policy levels, it takes a long time for a norm cluster to become robust. Diverging interests and value systems of states in different issue areas hamper translation and implementation, as happened in Bangladesh, where the disability inclusion norm lost out against the desire to contain refugee flows. When looking at the robustness of norm clusters, it is important to remember that robustness is indeed always partial; the robustness of the component norms can never be understood at only one level and varies over time.

From an empirical perspective, the idea of inclusion as a diverse norm cluster helps to explain the actual variation in norm development. At the international level, norm contestation—and attempts to avoid it—play an important role, but at the national level, norm evasion explains state behavior better. Whereas states still need to translate international norms better into their policies and advocacy, humanitarian organizations often lack the capacity to implement these four "must-do" actions with equal intensity. Put differently, at the organizational level, the robustness of the inclusion norm becomes a matter of capacity rather than evasion, contestation, and objection.

Many organizations have begun including the Washington Group Short Set on Functioning into their assessments and monitoring frameworks so that they can collect and analyze more disaggregated data, but they still fail to meaningfully engage the persons they identified in decision-making and programming. Similarly, despite adapting feedback mechanisms to make them more inclusive, many still struggle to respond to specific requirements of persons with disabilities and ensure

their meaningful participation, particularly when they have an intellectual disability, hearing impairment, high psychosocial needs, or multiple disabilities. It is therefore crucial to build capacity at the headquarters level and in field offices to accelerate both the translation into policies and the implementation of the norm cluster on the ground.

Crucially, disability inclusion is a strategic issue for the whole organization, and headquarters need to promote a diversity policy on gender, age, and other dimensions of diversity in all country operations. This will enhance equality, foster non-discrimination, and ensure the systematic incorporation of persons with disabilities in humanitarian activities at all stages of humanitarian action (preparedness, response, and recovery). Donor governments should do more to fund and facilitate these translation processes. Although a backlash of the disability inclusion norm cluster seems currently unlikely because its counterfactual validity is still strong, inclusion norms may become contested and lose relevance if they are not implemented well enough. Hence, studying norm robustness also requires more studies of actual translation and implementation over time.

In the introduction of this book, we asked two sub-questions. First, do norms really change the practices of the actors involved? And if so, how? Second, what is the impact of these norms on the lives of persons with disabilities? The answer to the first question is yes, humanitarian donors, mainstream humanitarian organizations, recipient states, inclusion-focused organizations, OPDs, and persons with disabilities have changed their practices, but only imperfectly so. Fostering disability inclusion is a long and arduous process that involves many actors across the various levels of global governance. Norms effect change, but only through perseverance and patience of these actors, especially during translation and implementation. There are setbacks; disability inclusion is not a linear process but requires constant reinforcement.

Answering the first question automatically leads to answering the second question. The lives of many persons with disabilities are changing for the better, but not enough. Most persons with disabilities still face heightened protection risks and problems with accessing humanitarian services. In this respect, neither praise nor pessimism are appropriate. The CRPD and the *IASC Guidelines* are crucial tools, but they still require far more support if they are to change the lives of persons with disabilities further.

7.4 Methodology

Methodologically, the above sections make clear that International Law and IR must incorporate more approaches from anthropology and comparative politics, including participatory action research and participant observation over time, to understand the impact of norms at the various levels of global governance. Otherwise, they cannot link norms and policies to the changes—or lack of them—in the lives of persons with disabilities and determine the robustness of global norm clusters. Hence, this book advocates for more multi-level mixed method and longitudinal research to norms on diversity and inclusion.

7.5 Issues for Further Research

In terms of a research agenda, the processes of institutionalization, translation, and implementation show that the different levels of global governance are related but cannot be reduced to each other. A next step in their study would be to ask how these levels constitute or at least shape each other mutually. Just as we need to ask what constitutes a collective or a community, we can ask how in the process of constituting collectives or communities, levels of global governance are being created (Roepstorff, 2022).

With research on humanitarian crises, more studies on the roles, functions, and impact of different norm clusters in International Law and IR are required to understand how they regulate or constitute practices of states, UN, NGOs, other non-state actors, and target groups. To assess their robustness, we also need more detailed actor-based studies on their translation and implementation: at the national level, involving governments; at the operational and strategic levels of an international humanitarian response, involving the Humanitarian Coordinator and Humanitarian Country Teams; in individual coordination clusters and other coordination mechanisms (such as the Central Emergency Response Fund, the Humanitarian Needs Overviews and Humanitarian Response Plans); and, finally, at the level of the individual organizations themselves, including their leadership, headquarters, and field offices. Just as we must understand the levels of global governance better, we also need to understand the different organizational levels better.

Crucially, we also need more research from the perspective of persons with disabilities and their OPDs. This often requires substantial participatory field research to gain a thorough understanding of their needs and capacities, local dynamics, coordination, and the duties, responsibilities, values, and interests of the organizations and authorities involved in the humanitarian response.

More generally, comparative research with other, sometimes overlapping or intersecting norm clusters (e.g., on gender, racism, LGBTQI+, or older persons) would also deepen our insight on norm development, robustness, and impact, as well as about the interaction of governmental and non-governmental action at various levels of governance. While this can be a challenging task, if done well, such International Law and IR research can shed more light on under-explored issues of human diversity, inclusion, and norm development in practice.

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