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Implementing the Inter-agency Standing Committee Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action: A Scoping Review

Dennis Dijkzeul[1], Sebastian Dempf[1*], Sena Göker[1] and Carolin Funke[2]

Abstract
The 2016 World Humanitarian Summit promoted the development of the Inter-Agency Standing Committee's *Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action*. These guidelines offer humanitarian actors practical information, enabling them to identify and respond to the needs, rights, and specific requirements of persons with disabilities, while taking their capacities into account. They outline the four "must-do" actions (MDAs) in humanitarian programming: (1) promote meaningful participation; (2) remove barriers; (3) empower persons with disabilities; support them to develop their capacities; and (4) disaggregate data for monitoring inclusion. This qualitative scoping review explores the specific role and (the degree of) impact of the *IASC Guidelines* and their MDAs on humanitarian practice. Our findings show that these guidelines bring together, build on, and reinforce earlier research. They also suggest that practical evidence of what does and does not work across humanitarian sectors and contexts is still limited. Interestingly, grey literature by humanitarian organizations pays more attention to the four MDAs than scholarly work. Greater awareness and application of the *IASC Guidelines*, particularly their four MDAs, are needed for meaningful progress towards more disability inclusive humanitarian action. This article also discusses issues for further research in this respect.

Keywords IASC guidelines, Disability inclusion, Scoping review, Must-do actions, Impairment

Introduction

Approximately 1.3 billion people, or 16% of the global population, live with some form of disability (WHO and World Bank 2011, p. 27; WHO 2022, pp. 2-3, 2023). Although most research on disability takes place in the Global North (e.g., Bolt 2014; Rinaldi and Rossiter 2018; van Toorn 2022), around 80% of persons with disabilities live in developing countries, where most humanitarian crises occur (WHO and World Bank 2011). Armed conflicts, disasters, climate change and other environmental degradation expose persons with disabilities to heightened risks, affecting their mental and physical well-being, safety, and survival. They often experience challenges in accessing essential services, early warning systems, evacuation routes, appropriate transportation, emergency housing, and necessary medical care. Moreover, they face limited access to livelihoods, employment, and educational opportunities, amplifying their vulnerability to poverty and marginalization (Funke and Dijkzeul 2021,

*Correspondence:
Sebastian Dempf
Sebastian.Dempf@ruhr-uni-bochum.de
[1]IFHV, Ruhr University Bochum, Bochum, Germany
[2]TU Dortmund University, Dortmund, Germany

p. 10). Their capacities[1] are noticed too rarely (Buscher 2018; Tanabe et al. 2018). Unsurprisingly, the disability rate in humanitarian crises and situations of displacement is often higher than 16%. A survey of adults in Afghanistan found a staggering 79% had a disability (Asia Foundation 2019) and estimates in Syria are that between 18 and 30% of the population has a disability (Skinner 2014; UN Syria 2019).[2] Polack et al. (2021, p. 1) reported that the overall prevalence of disability among Syrian refugees in the Sultanbeyli district of Istanbul was 24,7%.

To address these challenges, states, United Nations (UN) agencies, non-governmental organizations (NGOs), and global, regional, and national organizations of persons with disabilities (OPDs) adopted the *Charter on Inclusion of Persons with Disabilities in Humanitarian Action ("Humanitarian Disability Charter")* at the 2016 World Humanitarian Summit in Istanbul. This Charter aimed to promote the use of the *UN Convention on the Rights of Persons with Disabilities* (CRPD) in humanitarian crises. Notably, it initiated the development of the 2019 Inter-Agency Standing Committee's (IASC) G*uidelines on Inclusion of Persons with Disabilities in Humanitarian Action* (hereafter: *IASC Guidelines*). These guidelines offer humanitarian actors practical information, enabling them to identify and respond to the needs, rights, and specific requirements of persons with disabilities, while taking their capacities into account. They outline four "must-do" actions (MDAs) for all sectors and stages of the humanitarian program cycle: (1) "promote meaningful participation"; (2) "remove barriers"; (3) "empower persons with disabilities; support them to develop their capacities"; and (4) "disaggregate data for monitoring inclusion" (IASC 2019, p. 19f).

Theoretically, the CRPD is a normative framework with international legal status as a UN convention which the *IASC Guidelines* elaborates and specifies for the context of humanitarian crises. This scoping review shows that the four MDAs can be seen as norms – "shared expectations about appropriate behavior held by a collective of actors" (Katzenstein 1996, p. 5) – which are increasingly being institutionalized in international policy, but rarely fully translated into humanitarian policies or implemented in crisis settings.

Nevertheless, a growing number of humanitarian organizations[3] now officially integrate disability inclusion policies into their humanitarian activities,[4] driven in part by donor requirements and strategic documents that emphasize the imperative for more inclusive humanitarian action (DG Echo 2023; Mojtahedi et al. 2023; OCHA 2023). This article explores the specific role the *IASC Guidelines* have had in shaping humanitarian programs and projects. While we cannot quantify impact in terms of how many people were supported as a result of the *IASC Guidelines*, we can look at organizations that refer to and use them. We therefore ask: *How and to what extent do humanitarian organizations implement the IASC Guidelines' four "must-do" actions in their programming? What is known about the impact of the "must-do" actions on humanitarian practice?*

To answer these questions, this qualitative scoping review identifies gaps in and opportunities for the inclusion of persons with disabilities. This is thus a state-of-the-art review of a wide body of literature. It identifies how the *IASC Guidelines* are interpreted by practitioners and academics and outlines a range of recommendations. It aims to contribute to the conceptual and empirical work necessary to overcome barriers persons with disabilities face in humanitarian crises and to show potential enablers. It starts by providing a brief background on the development of the *IASC Guidelines* and their alignment with international legal and policy frameworks. After a methodological section, we present and discuss our empirical findings from both grey and academic literature. After a brief discussion of general aspects of the *IASC Guidelines* and their implementation, we examine each of the four MDAs in more detail. In our analytical discussion, we critically review the assumptions, strengths and weaknesses of the articles we included in our scoping review and provide suggestions for additional research to support humanitarian disability-inclusion efforts. The conclusions provide more general information on the implementation of these and other IASC guidelines.

Background

The publication of the *IASC Guidelines* in 2019 marked the culmination of an extensive, three-year collaborative process involving more than 600 stakeholders from the humanitarian, development, and disability sectors.

[1] Physical and mental, as well as legal, capacities in relation to their will and preferences (see Szmukler 2019).

[2] For a review of the latest demographical research see Funke and Dijkzeul (2025, p. 69).

[3] The International Committee of the Red Cross defines humanitarian organizations as "Entities with a mission to prevent and/or alleviate human suffering in armed conflicts. They are usually involved in: searching for, collecting and transporting the wounded and sick, missing and dead; providing medical treatment to the wounded and sick; assisting prisoners of war; and assisting the civilian population through the provision of humanitarian relief." (ICRC n.d).

[4] By 2022, almost all key UN entities had dedicated policies or guidelines on disability inclusion (Funke and Dijkzeul 2025). In 2020, the "International Committee of the Red Cross introduced The ICRC's Vision 2030 on Disability" (ICRC 2020) to promote, amongst other things, the routine collection, analysis, and use of data disaggregated by age, gender and disability, the recruitment and integration of staff with disabilities, and the accessibility of headquarters and delegations. Similarly, large international NGOs, such as Médecins Sans Frontières (MSF 2024; MSF OCBA n.d.; MSF 2021), Save the Children (Save the Children 2021), World Vision International (World Vision International 2024), and the International Rescue Committee (IRC 2021) published policies and guidelines.

Aiming to further institutionalize and promote the rights of persons with disabilities in humanitarian crises, this process built upon the foundations of earlier policies, strategies, guidelines, research, and legal frameworks. Crucially, the *IASC Guidelines* incorporate the human rights-based approach of conceptualizing disability. It contributes to the operationalization of the *UN Convention on the Rights of Persons with Disabilities (CRPD)*, in particular of its Article 11 on "situations of risk and humanitarian emergencies" (UN 2006). With its 20th ratification, the CRPD entered into force on 3 May 2008, marking a significant step in the institutionalization of the rights of persons with disabilities and establishing legally binding standards rooted in human rights.

Unlike the medical and charity models of disability, which focus on the individual and their impairment, the human rights-based model casts disability as socially constructed. As such, social exclusion arises not from the functional limitations of individuals with impairments, but from environmental barriers, attitudes, and cultures (Barnes 2012, p. 18).[5] Consequently, the *IASC Guidelines* suggest that inclusion "is achieved when persons with disabilities meaningfully participate in all their diversity, when their rights are promoted, and when disability-related concerns are addressed in compliance with the CRPD" (IASC 2019, p. 9).

Within humanitarian action, this involves a "twin-track" approach to programming: "First, mainstream humanitarian programmes and interventions, designed for the whole population, need to include persons with disabilities. […] Second, humanitarian programmes need to address the specific requirements of persons with disabilities by providing targeted interventions" (IASC 2019, p. 19). For both, the *IASC Guidelines* suggest the four MDAs and their corresponding "key actions" as the central way of increasing disability inclusion (Table 1).

The *IASC Guidelines* are not the only recent effort advocating for the rights of persons with disabilities. One year prior, the Age and Disability Consortium released the *Humanitarian Inclusion Standards for Older People and People with Disabilities* (HIS), which mirrored the structure of the well-established *Core Humanitarian Standard* (CHS Alliance et al. 2014) and is a Sphere companion volume. Similar to the *IASC Guidelines*, the *HIS* were developed in a consultative process involving stakeholders from various backgrounds "to help address the gap in understanding the needs, capacities and rights of older people and people with disabilities, and [to] promote their inclusion in humanitarian action" (Age and Disability Consortium 2018, p. 9). But while the *IASC Guidelines* and the *HIS* have much in common, they also display noteworthy differences. As *standards*, the *HIS* are primarily concerned with setting a baseline for principled humanitarian inclusion and provide high-level guidance on implementation only in a second instance. The *IASC Guidelines*, meanwhile, prioritize guidance, but focus less on describing the standards or outcomes they hope to

Table 1 The IASC Guidelines' four MDAs (IASC 2019, p. 20f)

Must-do action	Key action
Promote meaningful participation	• Enable persons with disabilities to participate in all processes that assess, plan, design, implement, monitor or evaluate humanitarian programs, in all phases and at all levels. • Recruit persons with disabilities as staff at all levels of humanitarian organizations, including as front-line workers and community mobilizers. • Seek advice and collaborate with organizations of persons with disabilities (OPDs) when you devise strategies for engaging with persons with disabilities in an affected community.
Remove barriers	• Identify all attitudinal, environmental and institutional barriers that prevent persons with disabilities from accessing humanitarian programs and services. Identify enablers that facilitate the participation of persons with disabilities. • Take appropriate measures to remove barriers and to promote enablers, to ensure that persons with disabilities have access to assistance and can participate meaningfully.
Empower persons with disabilities; support them to develop their capacities	• As a priority, develop the capacities of persons with disabilities and OPDs in the field of humanitarian action. Equip them with the knowledge, skills and leadership skills they need to contribute to and benefit from humanitarian assistance and protection. • Build the capacity of humanitarian workers. Assist them to design and implement inclusive humanitarian programs that are accessible to persons with disabilities by strengthening their understanding of the rights of persons with disabilities as well as principles and practical approaches that promote inclusion and reduce barriers to inclusion.
Disaggregate data for monitoring inclusion	• Where data are unavailable, humanitarian stakeholders, in partnership with OPDs, should collect data on sex, age and disability using a variety of tools tested in humanitarian contexts. These include the Washington Group Short Set of Disability Questions (WG-SS) and the UNICEF-Washington Group Child Functioning Module as well as data related to risks and barriers. • Use data on disability to monitor equal access, design inclusive programs, and plan their implementation. Ensure that persons with disabilities can participate at every level. • Disaggregating data by sex, age and disability makes it possible to develop appropriate indicators and use them to monitor the inclusion of persons with disabilities in all phases of humanitarian action.

[5] While both the human rights-based and social model understand disability as a social construct, the human rights-based model further advances the social model by recognizing disability as a natural part of human diversity and affirming that persons with disabilities enjoy the same rights and freedoms as all members of society (Degener 2016).

achieve. Although disability-focused organizations seem to rely more on the *IASC Guidelines* and age-focused organizations more on the HIS, more research is necessary to understand their differences and the respective levels of authority each document holds. This review focuses on the *IASC Guidelines* as they are exclusively dedicated to persons with disabilities – as opposed to the HIS which also cover older persons – and because of the IASC's special role within the humanitarian system: As the "the longest-standing and highest-level humanitarian coordination forum of the United Nations system" (IASC n.d.), it is in a unique position to shape the humanitarian agenda. Understanding how its high-level norms affect practice on the ground plays an important role in explaining how the humanitarian sector can change. Additionally, understanding the implementation and impact of the *IASC Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action* can also be relevant for understanding the functioning of the many other IASC guidelines.

Methods

To understand the *IASC Guidelines*' impact on humanitarian practice, we conducted a scoping review, collecting themes and insights from both grey and academic literature. Our approach followed Arksey and O'Malley (2005, p. 22) and consisted of five systematic phases: (1) "articulating the research question"; (2) "identifying relevant studies"; (3) "selecting eligible studies"; (4) "charting the data"; and (5) "collating, summarizing and reporting the results" (see also Dijkzeul and Borgmann 2022; Dijkzeul and Franzke 2022).

To identify relevant documents to assess the extent to which inclusion is pursued in humanitarian practice, we conducted searches in two practitioner-focused databases: ReliefWeb and the Active Learning Network for Accountability and Performance in Humanitarian Action (ALNAP).[6] These databases contain a wide range of grey literature, including reports, news bulletins, policy briefs, evaluations, and other material published by humanitarian, human rights, and development organizations not typically found in scholarly databases. In addition, we incorporated confidential project evaluations, proposals, and reports from two disability-inclusion NGOs, Humanity and Inclusion (HI) and Christian Blind Mission (CBM).[7] To identify academic literature, we focused on the scholarly databases Google Scholar and the Library Gateway from Ruhr University Bochum.[8]

Table 2 Expressions used to screen texts for reference to the MDAs

Must-do action	Expression(s)
Meaningful Participation	• Participation
Removal of Barriers	• Removing Barriers • Addressing Barriers
Capacity Development	• Capacity Development • Capacity Building • Empowerment
Disaggregated Data	• Disaggregated Data

We searched each database for results containing both "*IASC Guidelines*" and "Inclusion of Persons with Disabilities in Humanitarian Action". On Google Scholar and ReliefWeb, we applied date range filters to only return items from between 2019 – the year the *IASC Guidelines* were published – and the end of 2023. On ReliefWeb, we further added filters to remove 'News and Press Release[s]' as well as non-English items. ALNAP did not provide any filtering options. Using the results from these queries, we removed duplicates, irrelevant content types, non-English results, false positives that did not cover the *IASC Guidelines*, and six texts we were unable to access.

To further screen the contents of our corpus, we used Python to check each text for references to the four MDAs. Apache Tika was used to perform PDF text extraction, and the Natural Language Toolkit (NLTK) was used to remove stop words, split texts into sentences, and split sentences into words. Each sentence was then checked for expressions commonly associated with each MDA (see Table 2). Where multiple expressions existed – as in the case of *Removal of Barriers* and *Capacity Development* – finding any of them would yield a positive match for that text. For expressions consisting of multiple words (e.g., 'capacity,' 'building'), each of these words had to appear in the same sentence to yield a positive match. To account for various grammatical constructs, all keywords were stemmed before search, and both keywords and texts were converted to lower case (e.g., "Participation" ➜ "partici").[9] This step yielded a detailed overview of MDA coverage across databases.[10] Subsequently, we reviewed the texts prioritizing those mentioning multiple MDAs at once (see Fig. 1).

[6] ALNAP maintains the Humanitarian Evaluation, Learning and Performance (HELP) library, and offers search options for both this specific library as well as for its website as a whole. For this research, we queried the latter.

[7] HI and CBM were chosen as two of the scoping review's authors had previously partnered with them during Phase 2 and 3 of the Research Project: Leave No One Behind.

[8] We also searched Elsevier but applying the same search method yielded 0 results.

[9] We used the Punkt sentence tokenization model, Porter Stemmer and the default English stopwords from the NLTK corpus.

[10] Inadvertently, this approach meant that some reference to the MDAs were left uncovered. For example, the following sentence discusses the removal of barriers without using any of the expressions we searched for and would therefore have not led to a match: "An assistive device, such as a hearing aid, walking frame or a prosthetic device, may allow an EO survivor to start a small business, regain employment or resume responsibilities in the household" (Global Protection Cluster et al. 2020, p. 31).

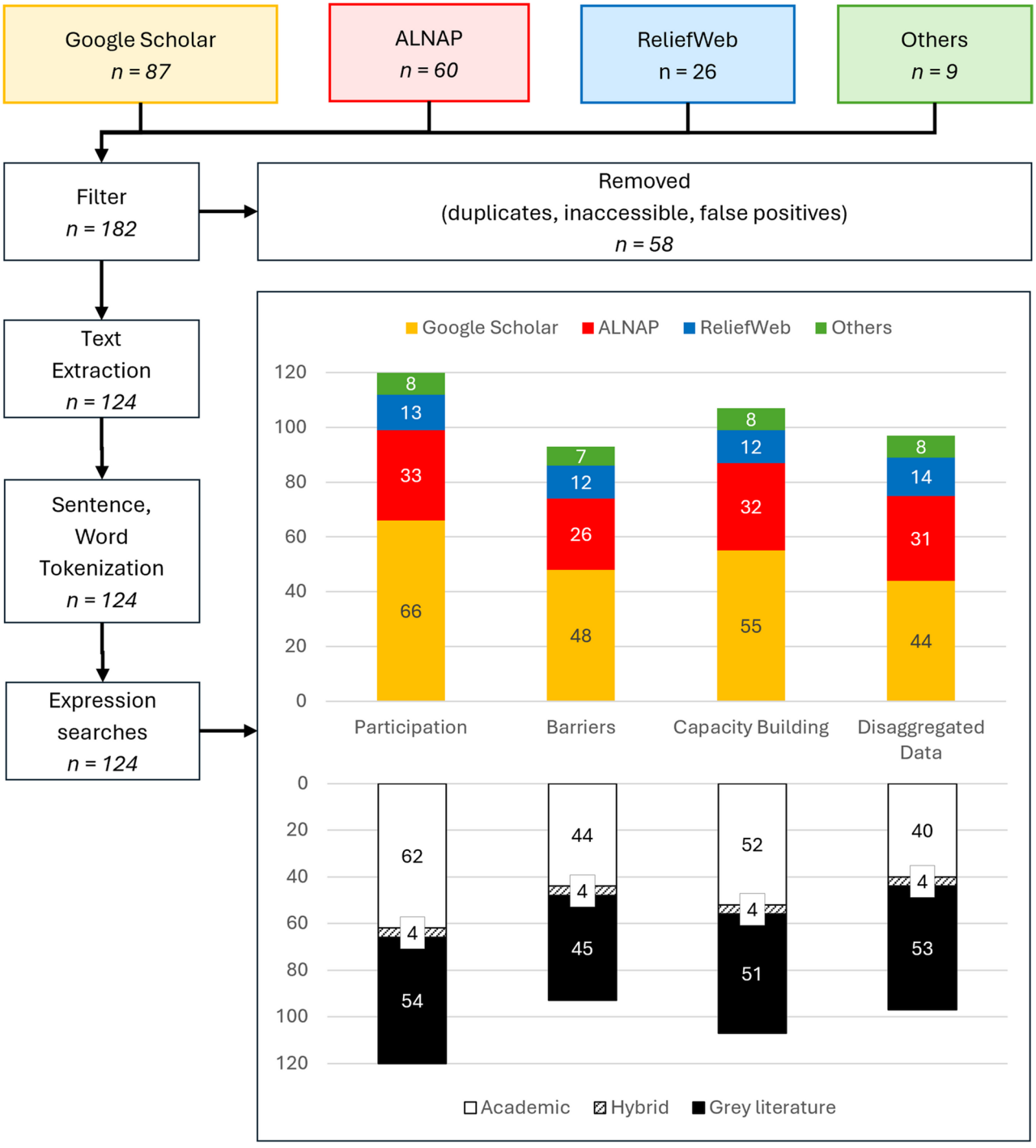

Fig. 1 Methodology. (The bar chart shows references of MDAs. A single article mentioning all four MDAs is therefore counted four times – once for every MDA.)

Empirical Findings

In this section, we present our empirical findings – first with regards to humanitarian organizations, then covering each respective MDA. The disability inclusion agenda already has a long history within humanitarian action. Separate searches for the terms "Disability Inclusion Humanitarian Action" yield results in all three databases for the past 20 years (see Fig. 2). This makes the task of discerning the impact of the *IASC Guidelines* on humanitarian practice difficult. There is evidence of a correlation between the release of the *IASC Guidelines* and the increased attention disability inclusion has received since – but whether this correlation implies causation is unclear. Our methodology produced texts that reference

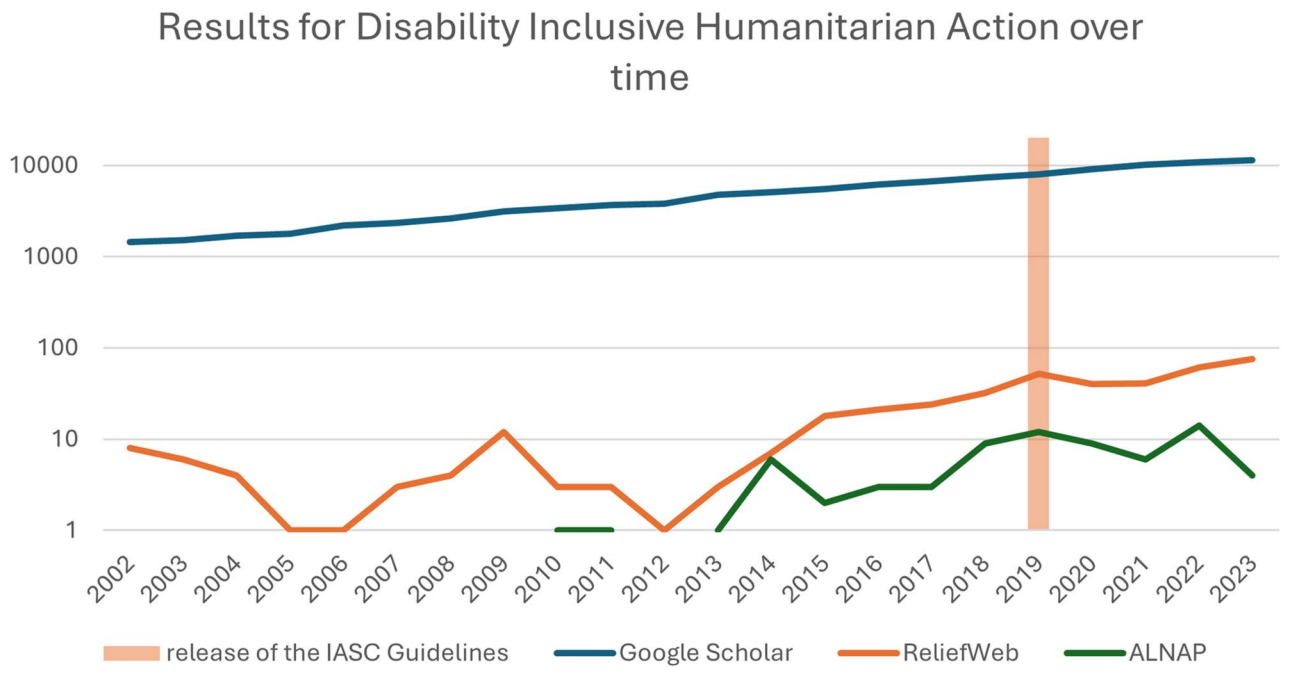

Fig. 2 Results for "disability inclusion humanitarian action" on Google Scholar, ReliefWeb, and ALNAP, disaggregated by year

the *IASC Guidelines* and frame specific issues and practices through the lens of the MDAs, but it did not provide evidence as to whether certain projects or programs have become more disability-conscious because of the *IASC Guidelines*. In fact, texts within our corpus frequently referred to other relevant guidance documents, including the "All Under One Roof" manual for disability-inclusive shelter programming (IFRC et al. 2015), United Nations High Commissioner for Refugees' (UNHCR) Age, Gender and Diversity Policy (UNHCR 2019a)[11], and the Guidelines for Providing Rights-Based and Gender-Responsive Services […] for Women and Young Persons with Disabilities (UNFPA 2018). This methodological challenge of dealing with various relevant guidelines is to be expected considering the gradual pace of (normative) change within the humanitarian system and was especially pronounced in texts from 2019 – the year the *IASC Guidelines* were released (CBM et al. 2019; DG Echo 2019; IASC and WRC 2019).

Crucially, although our methodology was partial towards texts adopting the language of the *IASC Guidelines*, we did not encounter any text that appeared to purposefully deviate from it. Building on previous research (see Fig. 2), the *IASC Guidelines* have codified a conceptual framework based on norms and scholarly work that had already found adoption within the disability inclusion movement and inclusion efforts more generally. Put differently, the *IASC Guidelines* turned out to be an articulation of existing normative frameworks, in particular the CRPD. While the extent to which texts incorporated this framework varied overall, some texts stood out in their embrace of the *IASC Guidelines*. Rothe et al. (2021), for example, develop their analysis of disability-inclusive cash assistance in line with the structure of the MDAs; M'Vouama et al. (2023) shape their recommendations on disability-inclusive climate change adaptation in Nepal around the MDAs; and Prasetyo et al. (2021) apply the language of the MDAs not just to persons with disabilities but also to vulnerable groups in general.

General issues for humanitarian actors across organizational levels

From a normative perspective, the content of the *IASC Guidelines* – the MDAs, grounded in the CRPD and the *Humanitarian Disability Charter* – enjoy strong recognition and have been widely adopted, built on, and translated into inter- and intra-organizational frameworks (DG Echo 2019; ALNAP 2020; OCHA 2020; IASC 2021; Rothe et al. 2021).[12] Planning frameworks, such as Humanitarian Needs and Response Plans, pay increasing attention to persons with disabilities ranging from short mentions to detailed elaborations on targeted response (IASC 2022, p. 64). Dedicated disability-focused coordination mechanisms have been established – including the

[11] UNHCR was an active contributor to the *IASC Guidelines* (UNHCR 2019b, p. 182).

[12] This is somewhat at odds with "the national legal and policy frameworks [which require] more improvement in order to adequately address the inclusion of persons with disability in situations of risk and humanitarian emergencies measures" (Islamic Relief Worldwide (Islamic Relief Worldwide 2021, p. 15).

Reference Group on Persons with Disabilities in Humanitarian Action at the global level and "some disability working groups at the country level" (UNICEF 2021, p. 76)[13] – and help promote the inclusion agenda (CBM et al. 2019; Barbelet and Palmer 2020). Additional guidance incorporating the *IASC Guidelines* and their MDAs have emerged too, for example on COVID-19 (IASC 2020a; UN 2020), Cash and Voucher Assistance (CVA) (Rodogosvky and Rattray 2022), and inclusive feedback mechanisms (IRC 2021).

However, despite this "strong basis for longer-term, systemic change" (Al Jubeh and Abdalla 2020, p. 11), many texts lament the "clear gap […] between strong corporate […] disability policies and operational realities" (Barbelet and Wake 2020, p. 20; ALNAP 2022, p. 146; Lough et al. 2022). Due to a lack of well-known, tried-and-tested measures for practical implementation, persons with disabilities continue to lack appropriate consideration (e.g., LFTW and UNICEF 2019; Bamenda Coordinating Centre for Studies in Disability and Rehabilitation 2020; IASC 2020; UNICEF 2021; de Clerck et al. 2023; Ngila Kikuni and Munenge Mudage 2023). In other words, this means that practitioners who know the *IASC Guidelines* still need more support on *how* to implement them.

Issues of prioritization and capacity are commonly mentioned as explanations for the gap between theory and operationalization. Because disability inclusion is one of many concerns in crisis contexts (Bula et al. 2020), whether to reach the many (= mainstreaming) or the most vulnerable (= targeting) entails difficult choices (ALNAP 2022).[14] Coupled with a lack of dedicated and long-term funding, humanitarian actors often lack the necessary resources to do both and to address disability inclusion sufficiently in practice (Frances et al. 2020; Lange 2020; Close 2021; ALNAP 2022; Ngila Kikuni and Munenge Mudage 2023). Donors are called upon in a twofold sense in this regard, in line with the twin-track approach: (1) they can channel their financial support towards projects specifically furthering the disability-agenda, and (2) they can "[c]ontinue to encourage accountability towards inclusion of persons with disabilities through required mainstreaming in proposals, implementation, M&E [i.e., monitoring and evaluation] and reporting" (UNFPA 2020; Mojtahedi et al. 2023). But while donor interest in disability-inclusive humanitarian action is rising (UNICEF 2021), "the right incentives for change are [only] set when donors have *internalized* commitments to inclusion" (CALP 2023, p. 24; own emphasis). Where donors subscribe to the inclusion agenda only by intent, where they focus on cost efficiency as their main metric of success, where their funding opportunities do not align with their demands, and where inflexible funding instruments limit long-term engagement and partnership building, their ability to instigate change is limited (Barbelet and Palmer 2020; UNICEF 2021). In short, "budgeting for ramps for toilets and other facilities" is not enough (Lough et al. 2022, p. 26).

The scoping review reveals a challenge for both donors and humanitarians in that much evidence of what works in disability-inclusive humanitarian action remains merely "anecdotal" (e.g., ALNAP 2022, p. 117; Wilbur et al. 2022).[15] As "being inclusive or impartial is not necessarily a well-defined criterion against which responses hold themselves to account" (Lough et al. 2022, p. 40), most M&E focuses on program outputs rather than on outcomes for affected people (ALNAP 2022). As a result, evidence is limited (see also Francis Watene 2022), and we found only a few examples detailing disability inclusion measures that have worked in practice (CBM et al. 2019; IASC and WRC 2019; Global CCCM Cluster 2022).

This lack of data also extends to persons with disabilities themselves. While data on affected populations is increasingly disaggregated by gender and age, disability-disaggregated data is still largely missing (Collinson 2020; Global Protection Cluster et al. 2020; Syria Protection Cluster 2021; ALNAP 2022; Ngila Kikuni and Munenge Mudage 2023; Syrian Protection Cluster 2023). "Most humanitarian actors lack even the most basic information about numbers and needs of people with disabilities and the threats and barriers they face in accessing services" (Collinson 2020, p. 16).

The intersectionality of various identity features – as highlighted by Bradley and Gruber (2021), Breffka and Martín (2020), Ćerimović (2023), Close (2021), Kett et al. (2021), Lovell (2021), and Tamiru and Melaku (2022) – is especially overlooked, leading to a "'cookie-cutter' approach [that fosters] rudimentary identity-based assumptions about people's vulnerabilities and needs" (ALNAP 2022, p. 147; Barbelet et al. 2022; Lough et al. 2022). The IASC Gender Handbook, for example, only suggests data disaggregation by disability 'where possible' which in turn has "fed into a perception that disability inclusion is a separate or specialist issue, and one which is either too difficult to manage, or the responsibility of specialist agencies" (Al Jubeh and Abdalla 2020, p. 11). This has negative effects on persons with intersecting identity features. For example, displaced persons with disabilities

[13] In this context, UNICEF laments that "disability is often dealt with as a subset of protection rather than as a programme element to be mainstreamed across sectors" (UNICEF 2021, p. 76).

[14] This also implies questions on how to define inclusion. Lough et al. (2022, p. 16) suggest that "inclusion does not imply a completist vision of meeting every need of every individual within a crisis. Rather, it involves a commitment to transparently analysing, documenting, negotiating and revisiting the challenges that responses face in determining who and what needs to be prioritised."

[15] The challenge of merely "anecdotal" evidence has been discussed long before the release of the *IASC Guidelines* (Jones 2013, p. 7).

are at risk of isolation from family, caregivers, and other support networks and resources, and women with disabilities continue facing higher risk of gender-based violence (GBV) due to the combined impact of stigma and gender inequality (Breffka and Martín 2020; Bamenda Coordinating Centre for Studies in Disability and Rehabilitation 2022). Children with disabilities may lack access to targeted humanitarian assistance (Ćerimović 2023) due to assumptions that they "do not understand or are not able to enjoy leisure activities" (Tamiru and Melaku 2022, p. 15), and older persons with disabilities are often categorized as older persons first with their disability-related needs becoming mostly invisible (Frances et al. 2020).

Still, the grouping together of older persons and persons with disabilities – as done by the HIS and some of the texts in our corpus (UNHCR 2019b; IASC 2020b; ASB Indonesia and the Philippines 2021) – seems to offer some benefits in this regard. Especially considering challenges with prioritization and capacity, such cross-cutting approaches addressing various measures together in a concentrated period of time are promising (Barbelet and Palmer 2020; Turcanu and Kahashi 2020). At the same time, there are limits to how far this grouping together of concerns can go. Creating a seemingly homogenous group of vulnerable persons fails to acknowledge the diversity of individual needs and capacities, as well as intersectionality (Barbelet and Wake 2020; Frances et al. 2020).

Promote meaningful participation

Persons with disabilities should be able to meaningfully participate in all phases of humanitarian responses. The studied literature frequently stated that working with local OPDs is an essential way of engaging with the community, identifying persons with disabilities, and involving them in implementation (LFTW and UNICEF 2019; UNHCR 2019b; Al Jubeh and Abdalla 2020; Breffka and Martín 2020; WHO 2020; Kett et al. 2021; Rothe et al. 2021; CBM Global Inclusion Advisory Group et al. 2022; Funke and Dijkzeul 2022; Global CCCM Cluster 2022). OPDs often face similar challenges as other humanitarian actors – a lack of capacity, systematic data collection, and long-term partnerships (CBM Global Inclusion Advisory Group et al. 2022) – but nonetheless manage to take on a variety of roles as advocates, advisors, and implementers. At times, this can result in "tension between the OPDs' primary roles as advocates and their roles in fulfilling their international partners' priorities" (CBM Global Inclusion Advisory Group et al. 2022, p. 26). Overall, persons with disabilities and OPDs are still "largely absent" from humanitarian decision-making (IASC 2020). Interestingly, we only found one reference to the importance of working with local researchers, who have a disability (InterAction 2021).

Building and sustaining meaningful participation of OPDs and persons with disabilities takes time and resources, which are especially lacking in crises – a rapidly growing problem (Frances et al. 2020; Lange 2020; Close 2021; ALNAP 2022; Ngila Kikuni and Munenge Mudage 2023). Short-term funding and funding insecurity may prevent the presence of humanitarian actors, reducing their ability to collaborate with affected communities and their knowledge about accessibility (Global CCCM Cluster 2022). To this end, multi-year, flexible funding plays a facilitating role in maintaining partnerships beyond the duration of crises (CBM Global Inclusion Advisory Group et al. 2022). It allows OPDs to maintain adequate levels of staff, which cannot always be ensured without it (Bula et al. 2020). In this respect, ongoing localization can help retain access over time (Barbelet and Palmer 2020), but whether it helps implement the *IASC Guidelines* depends on how inclusive specific local actors are (Al Jubeh and Abdalla 2020).

With regards to the *IASC Guidelines'* twin-track approach, the bulk of disability-inclusive programming continues to rest on the shoulders of disability-specialized organizations, and mainstreaming disability-inclusion across programs is still insufficient (e.g., Tamiru and Melaku 2022). Inclusion is often "framed more as something to do as a targeted activity rather than a mainstream element across programmes" (Barbelet et al. 2022; Lough et al. 2022, p. 7), which can have adverse effects for persons with disabilities. A report from Syria, for example, showed that while women and girls with disabilities already had access to local Safe Spaces, they preferred "integration at the Safe Spaces rather than having a separate programme, where they might feel excluded and which could further exacerbate stigma" (UNFPA 2020, p. 18). Especially smaller humanitarian actors with limited resources could benefit from mainstreaming the analysis of barriers and enablers into their projects, as this can drastically enhance access for various population groups without requiring expensive specialist programs or workstreams. In this sense, inclusion can be seen as a broader approach rather than an activity (Lough et al. 2022).

Table 3 Examples of OPDs and persons with disabilities embedded into humanitarian response

During CBM's 2014 Pakistan flood response, inclusive Village Development Committees, with persons with disabilities as members, facilitated communication, community ownership, implementation, and feedback processes (Rothe et al. 2021). In Mozambique and Somalia, persons with disabilities were embedded into Camp Coordination and Camp Management (CCCM) activities through their participation in focus group discussions and disability inclusion committees (Global CCCM Cluster 2022). The collaboration between UNHCR and the Lebanese Physically Handicapped Union achieved change in recruitment processes and helped remove physical barriers in local companies (UNHCR 2019b).

Remove barriers

Many authors indicate barriers that impede opportunities for persons with disabilities to participate in humanitarian activities (Breffka and Martín 2020; Close 2021; Funke and Dijkzeul 2021; Kett et al. 2021; Funke and Dijkzeul 2022; Global CCCM Cluster 2022); Kamnuansilpa and Lowatcharin 2022; Al-Dawoody and Pons 2023; Kan 2023).

In many cases, these barriers are environmental "includ[ing] physical obstacles in the natural or built environment that 'prevent access and affect opportunities for participation', and inaccessible communication systems" (IASC 2019, p. 8). Persons with disabilities often require assistive devices to increase their independence, yet access to such devices is largely limited, especially for older persons or those with multiple disabilities (McGivern et al. 2020). In a positive example from Somalia, "the CCCM Cluster supported referrals of persons living with disabilities to health practitioners working on assistive technology […] for further individual assessments and recommendation for tailored mobility aid. Dedicated funding was secured to procure assistive devices, provide transportation and accommodation to persons with disabilities to allow them to access rehabilitation centres" (Global CCCM Cluster 2022, p. 13).

Some humanitarian clusters have begun addressing these barriers by introducing cluster-specific guidance on disability-inclusive programming. For the Health Cluster, WHO suggests to "[e]nsure that services can be accessed by persons with reduced mobility [and] with non-mobility-related disabilities" and that "[d]irect observation and discussion groups with persons with disabilities in the community [should be used] to identify the type of adaptations that are needed" (WHO 2020, p. 19f). Echoing these recommendations, the Global CCCM Cluster reports that in Mozambique "service providers adapted the water points by adding a ramp, and latrines were adapted to respond to the needs of persons with disabilities." Additionally, they advise "[adapting] meetings and communication based on different types of disabilities (visual, physical, auditory)" (Global CCCM Cluster 2022, pp. 19-20). The Syrian Protection Cluster (2023) highlighted using the "RECU approach" to identify barriers in Reaching, Entry, Circulation, and Use in collective shelters in Northwest Syria. In cash transfer programs, similar tools, such as inclusive Feasibility and Financial Service Provider (FSP) assessments, enabled a more systematic and participatory approach to service design for addressing barriers (Rothe et al. 2021, p. 20). When left unaddressed, environmental barriers to accessing aid, such as distance or lack of information, can result in extremely "uninclusive" responses, as happened with Cyclone Idai in Mozambique (LFTW and UNICEF 2019).

Persons with disabilities face not just environmental barriers, however (e.g., Syrian Protection Cluster 2023). In Mozambique, the CCCM cluster discovered that the main barriers were "[a]ttitudes that reinforce discrimination, lack of livelihoods activities targeting persons with disabilities and lack of inclusive education" (Global CCCM Cluster 2022, pp. 19-20). LFTW and UNICEF (2019) noted not only discrimination and stigma by humanitarian actors and the communities but also a lack of accessible and adequate information and services. For Rohingya communities, REACH suggests "that diabilities [sic] may have been under-reported due to the stigma attached to disability […], particularly psychosocial disabilities" (HPN 2020). Tamiru and Melaku (2022, p. 24) report that refugees in Ethiopia "with intellectual disabilities tended to be more 'invisible' and 'hidden' from public view than those with physical disabilities. Some humanitarian workers considered intellectual impairment to be a mental problem, labelling people as 'mad' rather than as belonging to a category of persons with disabilities." To make matters worse, "legislation and policies [in Ethiopia] continue to employ derogatory terms such as 'insane', 'infirm' and 'deaf-mute' to refer to persons with disabilities" (Tamiru and Melaku 2022, p. 15).[16] From a humanitarian point of view, such contexts are difficult to address. While training and capacity building can break down *some* barriers, tackling more widespread and institutionalized barriers may go beyond a narrowly defined humanitarian mandate. In Cox's Bazar, Bangladesh, for example, working with local OPDs is made difficult by restrictive government regulations that prohibit Rohingya refugees from establishing their own organizations (Funke and Dijkzeul 2021). In conflict settings, "denial of humanitarian access by parties to the conflict" also limits what humanitarians can achieve (Whittaker and Wood 2022, p. 20).

Persons with disabilities often depend on others to support them in their day-to-day activities (Funke and Dijkzeul 2022). Hence, in some cases, humanitarian actors (also) direct their efforts at these caregivers instead of providing enablers or removing barriers for persons with disabilities themselves (LFTW and UNICEF 2019; CALP 2023). This increases humanitarian coverage but does not meaningfully address barriers for persons with disabilities. In the case of CVA for example, money is often channeled through intermediaries instead of being made available to persons with disabilities directly (CALP 2023), thereby increasing their reliance on caregivers (Rothe et al. 2021).

The digitalization of aid delivery – where appropriate – offers some opportunities in this regard. As CALP (2023) mentions in the case of CVA, these include remote

[16] The problem of discriminating, stigmatizing and derogatory terms has of course also been noticed before, for example by Degener (2011).

registration in hard-to-reach areas, access for those with mobility restrictions, better communication and feedback mechanisms, and more tailored service deliveries according to needs. At the same time, overreliance on digitalization risks leaving behind those with limited digital literacy and may have adverse effects on community engagement. Additionally, it raises questions on data protection and data subject rights (Lough et al. 2022). Finding the right balance poses a continuous challenge.

Table 4 Examples of UNFPA Jordan developing accessible IEC material

"UNFPA has developed IEC [i.e., information, education, and communication] material accessible to persons with disabilities, such as adapted videos, simplified easy-to-read versions, or versions for the visually impaired. Following the dissemination of adapted IEC material (and parallel improvement in the access of facilities, as well as training of service providers), UNFPA has registered meaningful (15 times) increases in people with disabilities accessing their services, including specialized case management, awareness sessions, recreational and life skills activities in safe spaces. According to the 2019 GBV IMS data, […] help-seeking behaviour of persons with disabilities improved significantly. In the context of the COVID-19 response, UNFPA Jordan released a video sharing information on hotlines available for survivours [sic] of domestic violence with sign language translation" (UNFPA 2020, p. 19).

Empower persons with disabilities; support them to develop their capacities

To equip "[h]umanitarian stakeholders […] to cooperate in ensuring that persons with disabilities are fully included in all aspects of humanitarian assistance and protection" (IASC 2019, p. 21), various reports highlighted capacity development initiatives. Overall, this MDA seemed to produce the most tangible examples of practical implementation.

Developing institutional capacity – often concerning human resources – is one enabler in removing barriers to disability inclusion. UNHCR, for instance, improved its staff capacity to support both institutional mainstreaming and disability inclusion efforts (UNHCR 2019b). Similarly, in Bangladesh, the CCCM Cluster worked with disability-focused experts for designing mobility aids, while in Somalia, two inclusion focal points enhanced accountability towards affected persons with disabilities (Global CCCM Cluster 2022). Interestingly, some of the necessary human resources seem to be available from the development sector, which has historically had more experience in inclusion than the humanitarian sector (Bioforce 2020).[17]

Many reports refer to staff training to build knowledge and increase organizational capacity, including IEC materials from CCCM in Mozambique (Global CCCM Cluster 2022), an e-learning program from UNHCR (2019b), or contextualized, peer-to-peer training on the *IASC Guidelines* such as the Bridge CRPD-SDGs initiative[18] (Barbelet and Palmer 2020; Fleury and Abdul Mumuni Ujah 2020). Working with OPDs on training and capacity building allows materials to be validated and spread to a wider community in a scalable fashion. In Nepal (pre-dating the *IASC Guidelines*), OPD leaders were trained and subsequently shared their knowledge with over 270 stakeholders (Global Protection Cluster 2020). Likewise, during the Zimbabwean response to Cyclone Amphan, local OPDs trained data collectors through mock interviews and joint reflection sessions, building confidence and enhancing communication with persons with disabilities (Rothe et al. 2021).

As with other areas of disability inclusion, training and capacity building is partially dependent on external factors such as the availability of funding, trainers, and opportunities to travel (Global CCCM Cluster 2022).

Table 5 Example of inclusion in Mozambique

As part of a CCCM initiative in Mozambique, "Twelve Disability Inclusion Committees were set up in Cabo Delgado. 120 Disability Inclusion Committee members were trained on the main concepts of CCCM and Protection against Sexual Exploitation and Abuse (PSEA). Thirty CCCM field staff were trained on the inclusion of people with disabilities in camp management activities. People with disabilities were included and active in the site management committee. [IEC] materials were developed for the promotion of disability inclusion. Government and service providers enhanced their knowledge and awareness of the rights and requirements of persons with disabilities" (Global CCCM Cluster 2022).

Disaggregated data for monitoring inclusion

Many authors observe that disability-disaggregated data continues to be rare and that this lack of data hinders progress towards disability inclusion[19] (Breffka and Martín 2020; Collinson 2020; Ryan et al. 2020; Carter and Kelly 2021; Kett et al. 2021; UNICEF 2021; Global CCCM Cluster 2022; Grech and Pisani 2022; Kamnuansilpa and Lowatcharin 2022; Tamiru and Melaku 2022; Wickenden et al. 2022; Ćerimović 2023; de Clerck et al. 2023). At the outset of crisis response, inclusive data practices require conducting inclusive needs assessments incorporating "a diverse sample of women, men, girls, and boys – including persons with disabilities, older persons, youths, and LGBTI persons" (OCHA 2020, p. 53; WHO 2020, p. 349). Later in the response, it involves disability-inclusive feedback mechanisms as outlined for example in the "Inclusive Client Responsiveness" toolkit developed by IRC

[17] UNICEF (2021, p. 77) supports this point: "There is a need to both train and support disability focal points, who often have a development focus, to engage more on humanitarian issues; and to train and support humanitarian focal points to be more disability sensitive."

[18] "It aims to support OPDs and disability rights advocates to develop an inclusive and comprehensive CRPD perspective on development (IDA 2021)" (Funke and Dijkzeul 2025, p. 74).

[19] While not a finding from this review, it seems that data availability has improved overall, but that – once collected – it is not analysed or used enough (see e.g., Mazurana et al. 2022, p. 46).

2021).[20] Collaborating with OPDs can help bridge some data gaps – either because they already have relevant data available or because they can help obtain it (Rothe et al. 2021) – but additional funding may be necessary for training and operational "resources […] to be translated into or co-created in local languages and accessible formats" (Frances et al. 2020, p. 20).

Importantly, ALNAP (2020, p. 16) points out that "waiting for better data and information shouldn't be an excuse for inaction: as one participant [at ALNAP's 32nd Annual Meeting] put it 'inclusion often seems to be premised on assessing everything, but we know enough to be inclusive and sensitive from the start' […]. Working assumptions can be made about the proportion of people who for example, have a disability or identify as gender non-binary […] This is the start of an iterative process of purposive and participatory information-gathering." This builds on the *IASC Guidelines'* own recommendation "to assume that 15 per cent of an affected population has a disability" where "robust quantitative data do not exist" (IASC 2019). As an example, Rothe et al. (2021) report in their "meta-analysis of humanitarian cash projects implemented by CBM", that "[i]n most of the responses, available data was complemented by data provided by local Organizations of Persons with Disabilities and through household surveys conducted by project staff. [But w]here no exact data were available, program staff […] estimated the number of households with persons with disabilities not represented in government data to be on average around 25% across different communities." Furthermore, the lack of data can be used to track exclusion by showing who is missing from the data, instead of indicating the lack of humanitarian needs or vulnerabilities (Barbelet et al. 2022).

Where data is collected, disaggregation by sex-, age-, and disability is not yet the norm (UNHCR 2019b; WHO 2020). The WHO Health Cluster Guide, for example, suggests disaggregation by "age, sex and geographical area" and includes only a weak appeal to "also be inclusive of vulnerable groups, such as persons living with disabilities" (WHO 2020, p. 151). It suggests this as a risk mitigation strategy for contexts where increased disaggregation across multiple dimensions simultaneously makes it more likely that marginalized individuals will be (re-)identified and put in harm's way. In addition, data collection itself may pose a risk for exposure and stigmatization of persons with disabilities (see M'Vouama and Bonnet 2024 on handling data and Chadwick and Vlahakis 2023 on GBV response). Depending on the context, however, thorough data protection measures might change how humanitarians weigh the risks of (re-)identification against being unable to reach a diverse range of affected populations.

Where disability data is collected, the Washington Group Short Set on Functioning (WG-SS) – "a standardized set of questions designed to identify people with disabilities during registration activities" (UNHCR 2019b, p. 182) – has been widely adopted (UNHCR 2019b; Turcanu and Kahashi 2020; Rothe et al. 2021; Global CCCM Cluster 2022; Lough et al. 2022).[21] This makes for better interoperability and comparability of data but does not come without its own set of challenges. First, "its use is seen as not viable or too time-consuming in emergency responses" (Young 2022, p. 407). Second, it requires "immense training" (Global CCCM Cluster 2022, p. 16) to ensure persons with disabilities are adequately reflected within the data. This becomes clear in an example from Nigeria, where "people with disabilities reported rarely if ever being consulted in humanitarian assessment processes, while heads of household were reluctant to even report their presence to external enumerators due to the social stigma of speaking about disability of family members to people outside the household" (Lough et al. 2022, p. 35). Third, the overreliance on seemingly objective quantitative data cannot reproduce the lived experiences of persons with disabilities. In a similar vein, complementary qualitative data is necessary to better understand barriers and enablers for meaningful participation, but is rarely collected (Barbelet and Wake 2020; Lough et al. 2022; Young 2022).

Table 6 Example of data infrastructure in Indonesia

"Collaboration between the Government of Indonesia and UNDP as part of the Sister Villages Programmes also included building the capacity of local authorities to address previous data gaps that made it difficult to reunite separated families and delayed the delivery of assistance. A central component of the programme is the Village Information System (VIS), which allows disaster response authorities to communicate essential operational information to affected community members throughout the response and recovery phase of a disaster. It includes village specific maps and plans and captures population data (disaggregated by age, disability or special assistance requirements), infrastructure information, livestock numbers, and hazard risk information to inform short and long-term district-level budgeting and assistance delivery" (Global Protection Cluster 2020, p. 50).

Analytical Discussion

Across our corpus, the evidence from grey literature and scholarly work differed in scope and quality. In this section, we discuss the differences between them while

[20] While technically a piece of guidance itself, the toolkit provides tangible information on how to design, implement, and monitor inclusive feedback mechanisms, ranging from advice on barriers to be mindful of, to suggestions for language that should be avoided, to templates of spreadsheets for data collection.

[21] "The Washington Group has developed [several] tools to measure disability in line with the functional approach of the WHO's International Classification of Functioning, Disability, and Health" (Funke and Dijkzeul 2025, p. 70). The Washington Group Short Set of Questions are the best known, but there are several other ones.

critically reviewing the assumptions, strengths and weaknesses of the findings (Wright and Michailova 2023).

Looking at our findings, the four MDAs do not enjoy equal attention. Meaningful Participation was referenced the most in our corpus (see Fig. 1) and appeared at times to be used synonymously with inclusion more broadly. The remaining MDAs are often seen as means to the end of meaningful participation. Interestingly, while no article disagreed with the central role disaggregated data plays for the disability inclusion agenda, this MDA seemed to draw the most criticism with regards to its slow and incomplete implementation. Even if data is collected, many humanitarian workers do not know how to analyze it properly. And even when it has been analyzed, many humanitarian workers do not know how to translate it into effective policies, programs, and projects (M'Vouama and Bonnet 2024). At the same time, several authors pointed out a lack of disaggregated data does not preclude inclusive humanitarian action. These are central problems for the implementation of the *IASC Guidelines*. The MDAs do not need to be reformulated or updated, but more needs to be done for humanitarian actors to strengthen their capacities to implement them.

Turning to academic literature, attention to disability-inclusive humanitarian action is growing overall but rarely prioritizes the effects of disability norms such as the *IASC Guidelines* on daily humanitarian practice.[22] Instead, the academic literature we analyzed focuses more immediately on the lives of persons with disabilities, how they are affected, and what can be done to support them. Where scholars reference the *IASC Guidelines*, they usually do so to contextualize disability inclusion, but broader – and often older – legal and policy frameworks (e.g., CRPD, SDGs) appear to receive greater attention. Unsurprisingly, as a foundational legal text, the CRPD was referenced frequently as highly influential in codifying the human rights-based model of disability (e.g., Priddy 2019; Izutsu et al. 2021; Lord and Stein 2022; Breitegger 2023).[23]

Some studies nonetheless describe the *IASC Guidelines* as a significant shift toward disability inclusion (Francis Watene 2022). Some scholars use them as a source of disability-related principles (Grech and Pisani 2022; Pearce et al. 2022), and only a few focus explicitly on their practical implementation. Among this last group, Funke and Dijkzeul (2021, 2022) analyze the implementation of all four MDAs in Bangladesh and South Sudan, and Kusumowardoyo and Tamtomo (2021) focus on the role of data disaggregation in disaster risk reduction in Bangladesh. Other studies touch on program delivery without explicit linkage to the *IASC Guidelines* (Whittaker and Wood 2022), and some literature focuses specifically on disability inclusion during the COVID-19 response (Velasco et al. 2021; Farhin and Basri 2022; Botha et al. 2023) but lacks attention to implementation. The adoption of the language of the MDAs to vulnerable groups more generally (Prasetyo et al. 2021), suggests that the *IASC Guidelines* are widely applicable and can be adapted to humanitarian guidelines for other vulnerable groups, too.

Interestingly, both academic and grey literature thus build on a normative, human rights-based foundation to analyze the state of disability inclusion but pay little attention overall to the role of the *IASC Guidelines* in bringing about changes in humanitarian behavior. This pattern reinforces our argument that despite greater policy attention, operational concerns of translating norms into practice are still largely overlooked. As stated, practitioners need more support on *how* to implement and evaluate the *IASC Guidelines* which is reinforced by the *IASC Guidelines*' own call for capacity development to apply a more practice-oriented lens. Scholars, meanwhile, need to study the translation of high-level norms into donor and organizational policies, as well as implementation into daily practice more.

Focusing on practice itself, grey literature – especially from disability-focused and other international organizations – frequently offers more actionable insights for the four MDAs than scholarly works (e.g., CBM et al. 2019; Global CCCM Cluster 2022; Rodogosvky and Rattray 2022; HI Bangladesh 2023; M'Vouama et al. 2023).[24] In many cases, this is the result of collaborating with OPDs and being willing to document and share achievements and challenges alike. Even where an "instrumental approach" focusing narrowly on disability within sector-specific mandates is adopted (Lough et al. 2022, p. 27), valuable contributions can emerge. Considering the wider humanitarian sector, however, there is less information about disability-inclusive practices from non-specialized and smaller organizations. This is likely the result of the fact that many organizations perceive (disability) inclusion as an additional, targeted activity that requires additional funding and capacity. In this sense, the *IASC Guidelines*' twin-track approach, or the suggestion of Lough et al. (2022) to conduct basic barriers and enablers analyses in mainstream programming where resources are limited, are not yet well adopted. Although, this could

[22] See Funke and Dijkzeul (2025) for an exception. This volume was published after data collection closed.

[23] It is likely that the *IASC Guidelines* will receive more scholarly attention in the future.

[24] These grey papers have mainly been drafted to provide practical guidance for humanitarian actors. In this respect, disability-focused NGOs have a mandate to promote disability inclusion. It is important to keep in mind the different purposes of the two categories of work. Even though grey literature is not (always) peer reviewed, some grey literature is very informative and of a high quality.

also mean that the *IASC Guidelines* do not always reach smaller organizations.

Where disability inclusion works well, it engages persons with disabilities, OPDs, and local organizations into project design, management, delivery, coordination, and evaluations. Successful efforts employ a twin-track approach, address barriers to the extent possible, identify enablers, deliver contextual training, and utilize disaggregated data for both planning and monitoring. Yet, broader implementation of such practices across the humanitarian sector remains insufficient. Greater awareness and application of the *IASC Guidelines*, particularly their four MDAs, could promote a more comprehensive approach to disability inclusion and improve accountability for persons with disabilities. Disability-focused organizations already have a wealth of knowledge, documents, and training materials to inform broader, more mainstream approaches across the humanitarian sector. However, a variety of challenges continue to hinder such efforts. Much of the knowledge that is already available cannot be operationalized easily. Institutional and other barriers, a lack of funding (especially in light of recent, drastic budget cuts), the inability for long-term programming, and high staff turnover further limit the progress of humanitarian actors large and small.[25]

Future research on disability inclusion in humanitarian action should focus on involving persons with disabilities, not only to generate more relevant outputs, but also to develop "a pool of researchers with disabilities who can provide strategic advice and technical support […] in the future" (InterAction 2021, p. 6). Checking the assumptions, strengths and weaknesses from the scoping review, five topics stand out:

1. There is still limited practical evidence of what does and does not work across programming sectors and contexts. A robust body of comparative case-based evidence, as well as more quantitative data (e.g., from impact assessments, meta evaluations, or specialized studies), could help inform future program design within humanitarian action across different sectors and settings. Much of the research focuses on outputs of OPDs, disability-focused organizations, and other humanitarian organizations, and to some extent the communities they intervened in. There is some literature on outcomes, but little on impacts. In this sense, more attention should be given to country or regional responses and system-wide evaluations, while using the OECD-DAC humanitarian (and development) evaluation criteria.
2. As stated, we have included additional literature by two inclusion-focused organizations (HI and CBM) in our corpus. Future research could place a stronger focus on both international and national mainstream humanitarian organizations, as well as on OPDs.
3. The scoping review took place before the recent drastic cuts in humanitarian funding. Since a lack of capacity has been holding back inclusive humanitarian action even before, understanding where additional resources could come from is important to meaningfully advocate for more inclusive programming. In addition, finding ways to implement inclusion, while dealing with a lack of resources, continues to require more research. This includes the questions of (1) how humanitarians strike the optimal balance between mainstreaming and implementing targeted activities following the twin-track approach, and (2) how to combine attention to persons with disabilities with other cross-sectoral themes, such as gender, age, ethnic or religious minorities, or more generally with preventing sexual exploitation and abuse, and accountability to affected people (see also point 5 below).
4. Managing resources also implies managing the change they can enable. A comprehensive account of how humanitarian goals and ideas are translated into mainstream humanitarian action would likely extend beyond the *IASC Guidelines*, and consider a variety of stakeholders, factors, and resources to inform a general humanitarian theory of change. It can build on previous work by Funke and Dijkzeul (2021, 2022, 2025) who researched disability inclusion in Bangladesh and South Sudan, and demonstrate that change has emerged from both top-down policy commitments and bottom-up advocacy and practice – with donor requirements, local engagement, and demands for accountability from persons with disabilities being essential drivers of progress. As guidelines like the *IASC Guidelines* tend to consolidate what is known about a topic at a specific point in time, close research with practitioners could further illuminate their unique impact on humanitarian practice.
5. The *IASC Guidelines* are one of many guiding frameworks – such as the HIS, UNDIS or organization-specific guidelines –, and the sheer

[25] In response to drastic budget cuts, Emergency Relief Coordinator Tom Fletcher proclaimed the Humanitarian Reset in March 2025 – a sweeping 10-point reform plan for the humanitarian system (OCHA 2025). While much of it is still on its way, it could have far-reaching effects for persons with disabilities. If funding cuts and cluster mergers dilute specialized protection and accessibility measures, it will likely further exacerbate current barriers. But if it prioritizes the most vulnerable, embraces 'locally led' principles, and embeds disability inclusion from the outset – by involving persons with disabilities and OPDs in decision-making, safeguarding dedicated resources, and integrating accessibility into all clusters – it could shift the system toward responses that are not just reactive but also more equitable and sustainable for persons with disabilities.

volume of all humanitarian guidance can overwhelm individual practitioners and researchers alike. While the *IASC Guidelines* already brought together and consolidated much previous research and experience, the practice of synthesizing, focusing, and reinforcing existing guidelines and research further is a helpful mechanism to enhance their overall implementation and evaluation. In addition, it may help to consolidate (some of) the many guidelines. In the context of disability inclusion, this for example involves a better understanding of the relationship between the *IASC Guidelines* and the *HIS*. In addition, we also found limited evidence that the four MDAs can be used for other vulnerable groups (Prasetyo et al. 2021). Logically, meaningful participation, reducing barriers, developing capacities, and disaggregating are useful for all vulnerable groups.

Conclusions

Humanitarian actors acknowledge the effect diversity has on an individual's experience of crisis and have signed on to better incorporate the needs and capacities of a diverse range of crisis-affected populations into their programming. For persons with disabilities specifically, progress has been limited as they continue to experience greater risks of being left behind in humanitarian crises. The normative force of disability inclusion appears to be strong, but a lack of practical capacity for implementation has limited what humanitarian actors are able to do. Institutionalization of the *IASC Guidelines* and their MDAs at the international legal and policy level is ahead of translation into donor governments' and humanitarian organizations' policies and actual implementation on the ground.

This places the *IASC Guidelines* at an interesting spot at the intersection of advocacy and application. Broad international treaties like the CRPD may enjoy greater normative authority while sector-specific guidance on disability-inclusive program design may be more relevant practically. However, the *IASC Guidelines* play an important role in articulating and highlighting the CRPD for a specific audience. The fact that no text in our review consciously deviates from the *IASC Guidelines'* core ideas and that they are frequently cited by both practitioners and scholars, testifies to the acceptance of the disability inclusion agenda and norms in humanitarian action. In this sense, the *IASC Guidelines* help to focus action. Although their implementation is hampered by a lack of resources and practical knowledge on how to apply them, they have become an integral part of the efforts to realize disability-inclusion within humanitarian action.

Abbreviations

Abbreviation	Meaning
ALNAP	Active Learning Network for Accountability and Performance in Humaitarian Action
CBM	Christian Blind Mission
CCCM	Camp Coordination and Camp Management
CRPD	UN Convention on the Rights of Persons with Disabilities
CVA	Cash and Voucher Assistance
FSP	Feasibility and Financial Service Provider
HI	Handicap International / Humanity and Inclusion
HIS	Humanitarian Inclusion Standards for Older People and People with Disabilities
IASC	Inter-Agency Standing Committee
MDA	"Must-do" action
NGO	Non-governmental organization
NLTK	Natural Language Toolkit
OPD	Person with disabilities
PSEA	Protection against Sexual Exploitation and Abuse
UN	United Nations
VIS	Village Information System
WG-SS	Washington Group Short Set of Disability Questions

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S.D., S.G., and D.D. wrote the main manuscript text, developed the methodology, and prepared the figures.C.F. helped with the conception of the article, worked on the initial draft, and provided feedback on later versions.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Not applicable. Ethical approval was not required for this scoping review as it is based on analysis of publicly available literature and does not involve human participants.

Consent for publication

We consent to the publication of this article.

Competing interests

The authors declare no competing interests.

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