Gap Analysis: the Inclusion of People with Disability and Older People in Humanitarian Response

Part 2
Beyond the evidence: Implications for innovation and practice

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HIF Humanitarian innovation fund | elrha

ABOUT ELRHA

We are a global charity that finds solutions to complex humanitarian problems through research and innovation.

We fund and support work that goes on to shape the way in which people across the world are supported during a crisis. An established actor in the humanitarian community, we work in partnership with humanitarian organisations, researchers, innovators, and the private sector to tackle some of the most difficult challenges facing people all over the world. Our shared aim as collaborators is to improve the effectiveness of humanitarian response.

The innovations we fund through our Humanitarian Innovation Fund (HIF) target better outcomes for people affected by humanitarian crises by identifying, nurturing and sharing more effective and scalable solutions. We have supported more than 200 world-class research and innovation projects, championing new ideas and different approaches to find what works in humanitarian response.

Our strategy includes a commitment to the inclusion of marginalised and excluded population groups within humanitarian response. We believe humanitarian innovation has much to contribute to this agenda. In 2019 we developed a new focus area: the inclusion of people with disabilities and older people. With funding from the UK Foreign, Commonwealth and Development Office (FCDO) we are exploring the barriers to, and supporting opportunities for, the inclusion of older people and people with disabilities in humanitarian response. To date we have launched four Innovation Challenges and are supporting a growing portfolio of projects.

THIS REPORT

As our work is problem-led and evidence-based, we commissioned the Nossal Institute to undertake a Gap Analysis on the inclusion of people with disability and older people in humanitarian response and to author this report.

In July 2020 we published a report presenting the findings of Part 1 of that Gap Analysis: a review and mapping of academic and grey literature. Additional findings from Part 2 of the Gap Analysis are now presented in this second and final report. This report includes findings from interviews, online workshops, and a consultation in Indonesia.

ABOUT THE AUTHORS

NOSSAL INSTITUTE FOR GLOBAL HEALTH, UNIVERSITY OF MELBOURNE

The Nossal Institute works on practical solutions to pressing global concerns, combining real-world experience with the scientific rigour of one of the world's top universities. Its big picture perspective helps build a deep understanding of complexity and change and integrate that understanding into country and regional strategies. Through the Institute's Disability Inclusion Team, mainstream and targeted solutions improve service delivery, strengthen data and measurement, and reduce risk for people with disability and others with access and functional needs.

ARBEITER – SAMARITER – BUND DEUTSCHLAND E.V

Arbeiter-Samariter-Bund (ASB) is a German relief and social welfare organisation established in 1888. ASB is engaged in a wide range of social service provision in Germany and abroad, including civil protection, rescue, and social welfare services. ASB is a founding member of the Disability-inclusive Disaster Risk Reduction Network (DiDRRN) and member of the Disability Stakeholder Group: Thematic Group on Disaster Risk Reduction (DRR). Through DiDRRN, ASB leads collective efforts to influence inclusion and Disaster Risk Reduction (DRR) in regional and global policy processes supported by practical lessons and evidence.

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ABBREVIATIONS

ASB: Arbeiter-Samariter-Bund

CHS: Core Humanitarian Standard on Quality and Accountability

CRPD: Convention on the Rights of Persons with Disabilities

DPO: Disabled Person's Organisations

DRR: Disaster Risk Reduction

HIS: Humanitarian Inclusion Standards for Older People and People with Disabilities

IASC: Inter-Agency Standing Committee

KII: Key Informant Interview

NGO: Non-Governmental Organisation

OPA: Older People's Association

OPD: Organisation of Persons with Disability

UN: United Nations

GLOSSARY

Barriers: Prevent an individual or group from participating in humanitarian response, or society, on an equal basis with others. Barriers are not only physical. Barriers can also be attitudinal, informational, technological or institutional.

Capacity Development: Improving the skills, competencies and abilities of people, along with processes and resources to support them in their work.

Innovation: Elrha defines innovation as an iterative process that identifies, adjusts and diffuses ideas for improving humanitarian action.

Intersectionality: The interaction of factors, such as disability, age and gender, which can create multiple layers of discrimination and exclusion. These can further hinder a person's access to, and participation in, humanitarian response, and society.

Localisation: The process of moving towards increased delivery of humanitarian assistance at the local level, including increasing local leadership by, and the allocation of funding to, local humanitarian actors.

Meaningful Participation: Full and effective involvement in decision-making, including in the design, development, implementation, monitoring and evaluation of humanitarian programmes, policies, and interventions. Participation is an individual choice and should not be limited by an individual's identity or any external barriers.

Medical Model: Understanding of disability that focuses on an individual's health condition or impairment (c.f. Social Model).

Reasonable Accommodation: Adaptations to meet the accessibility needs of individuals with disabilities.

Social Model: Understanding of disability that emphasises the disabling nature of barriers in society (c.f. Medical Model).

Sphere: Initiative that developed the Humanitarian Charter, Sphere Standards and Handbook for Humanitarian Response.

Thematic Analysis: A method of analysing qualitative data, such as interview transcripts, involving the identification of themes or topics.

Twin-track: Approach to disability inclusion that includes mainstreaming activities to remove barriers alongside targeted interventions for people with disability.

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We thank everyone who has provided invaluable input into this report and Gap Analysis project.

In particular, the members of our dedicated Steering Committee who engaged so enthusiastically, providing helpful feedback along the way. Thank you to all those who were interviewed, who took part in and supported the consultation in Indonesia, and who participated in online workshops. We also thank the UK Foreign, Commonwealth and Development Office (FCDO) for the support that made this work possible.

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A

SECTION A

INTRODUCTION AND APPROACH

1.0

INTRODUCTION

1.0 INTRODUCTION

The Gap Analysis was commissioned by Elrha to build the evidence base on inclusion and to inform priorities for innovation. **This was the first ever piece of work to systematically review the evidence on the inclusion of people with disability and older people across humanitarian response** and to assess how this evidence connects to practice.

In Part 1 of the Gap Analysis on the Inclusion of People with Disability and Older People in Humanitarian Response, we identified and reviewed academic and grey literature. We found limited evidence on the inclusion of people with disability and older people being included in humanitarian response, despite these groups being disproportionately impacted by disasters, conflict, and humanitarian crises. Building on that literature review, **this report presents Part 2 of the Gap Analysis, which gathered insights from individuals working in humanitarian response, disability inclusion, and older age inclusion.**

Together, Parts 1 and 2 of the Gap Analysis aim to inform more inclusive humanitarian response. They will help humanitarian actors and representative organisations better identify challenges, prioritise interventions, and build on opportunities for increasing inclusion across all sectors of humanitarian response.

The Gap Analysis was led and authored by the Nossal Institute for Global Health at the University of Melbourne. The Nossal Institute team was supported by Arbeiter-Samariter-Bund's Office for Indonesia and the Philippines (ASB) in the review of grey literature. ASB also facilitated a consultation with people with disability and older people in Indonesia. The Gap Analysis process was guided throughout by a dedicated Steering Committee co-chaired by Elrha and the Nossal Institute. The Steering Committee was composed of representatives from humanitarian organisations, Organisations of Persons with Disability (OPDs) and Older People's Associations (OPAs).

This report begins with a summary of the overall aims of the Gap Analysis and a recap of the findings from Part 1. It then sets out the approach to data collection for Part 2 and presents the findings. The findings begin by looking at how an agenda for the inclusion of people with disability and older people in humanitarian response has been established

We then consider how guidance and standards are informing humanitarian practice and the challenges associated with translating commitments into practice. Finally, we present seven areas that have potential for innovation in research and practice.

1.1 AIMS

The overall aim of the Gap Analysis was to understand:

What is the evidence on the inclusion of people with disability and older people in humanitarian response?

Our guiding question for Part 2 was:

How does available evidence lead to better inclusion of people with disability and older people in humanitarian response, and what are the barriers to effective uptake of evidence and good practice?

The additional objectives of Part 2 were to:

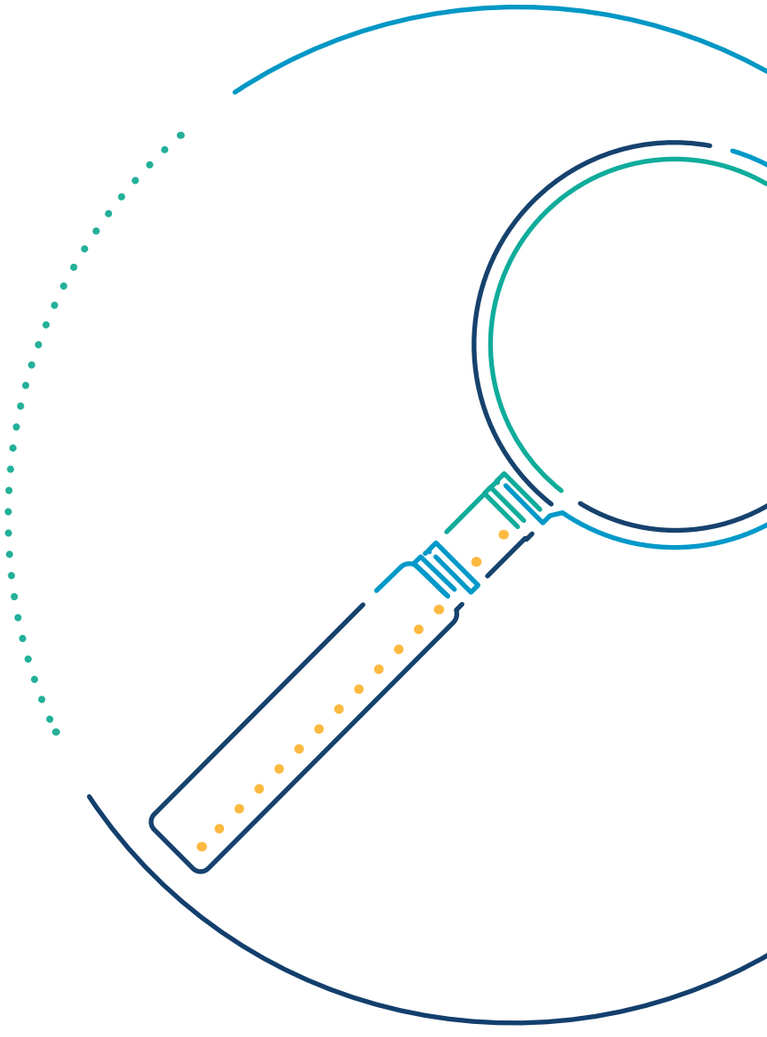
- Ensure real-world experience was used to understand and interpret findings from the literature review.
- Learn from experts in the field about how they are using evidence, information and guidance in practice.

1.2 SUMMARY OF LITERATURE REVIEW FINDINGS

The Gap Analysis has been conducted against a backdrop of increasing global commitments to inclusion in humanitarian response. This includes the Sendai Framework for Disaster Risk Reduction 2015-2030 and Charter on Inclusion of Persons with Disabilities in Humanitarian Action, 2016.[1,2] Both of these are informed by Article 11 on Situations of Risk and Humanitarian Emergencies of the UN Convention on the Rights of Persons with Disabilities (CRPD), 2006.[3]

Recent years have seen an increase in the number of publications addressing either the inclusion of people with disability or older people in humanitarian response. In particular, there has been a sustained increase in the number of publications addressing disability inclusion over the last five years. While there are fewer publications on the inclusion of older people, there has been a notable increase in these since 2018. Similarly, we have seen the development of humanitarian standards and guidance - notably, the Humanitarian Inclusion Standards for Older People and People with Disabilities (HIS), 2018 and the Inter-Agency Standing Committee (IASC) Guidelines: Inclusion of Persons with Disabilities in Humanitarian Action, 2019.[4,5]

The HIS are based on the Nine Commitments of the Core Humanitarian Standard on Quality and Accountability (CHS), and were adopted as part of the Sphere community standards in 2019.[6] The twin aims of the HIS are to hold humanitarian actors to account on commitments to inclusion and to support the participation of people with disability and older people in humanitarian response. Similarly, the recent IASC standards aim to translate CRPD commitments and the 2016 Charter into action.

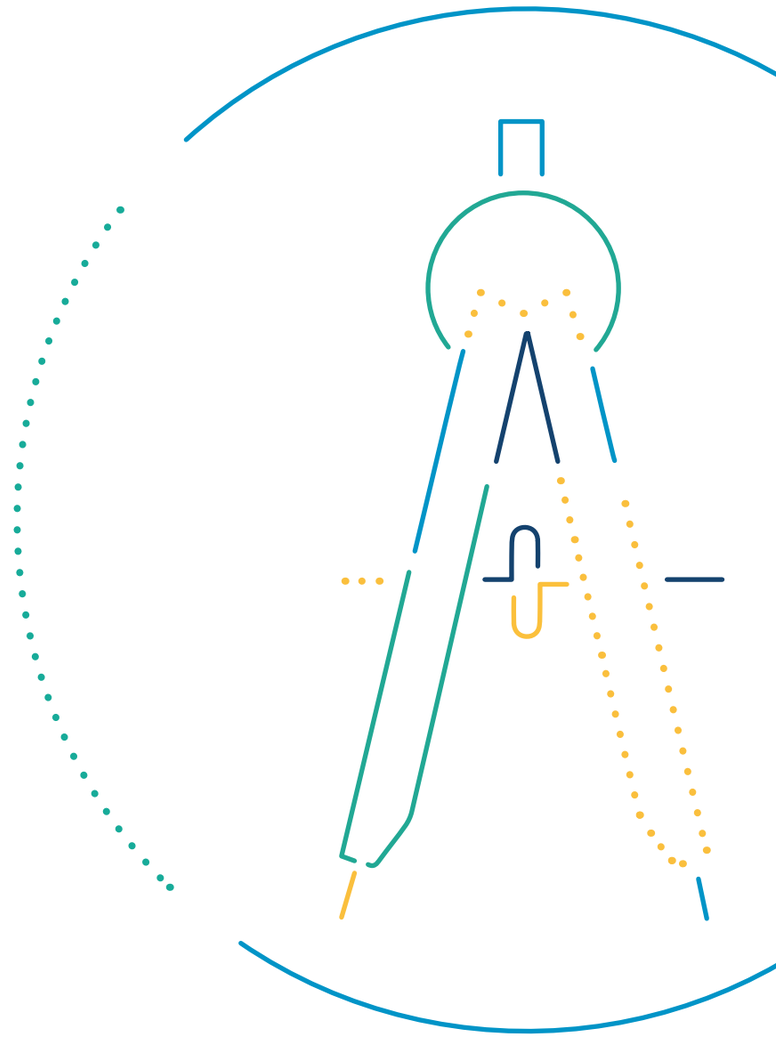


1.2 SUMMARY OF LITERATURE REVIEW FINDINGS

Overall, in Part 1 of the Gap Analysis we found the evidence from the literature on the inclusion of people with disability and older people to be limited and of mixed quality. We mapped evidence against the nine core HIS standards alongside sectors identified from the literature, such as shelter, health and communications. Through this mapping, we found the evidence to be scattered and lacking in depth. The mapping matrices from the literature review are reproduced in this report (Tables 1 and 2). The numbers in the matrices refer to the number of articles directly addressing that HIS and sector.

Alongside the gaps indicated by the areas with no numbers on the matrices below, the literature review noted significant gaps overall. These included a lack of evidence on the effectiveness of efforts to improve inclusion; limited evidence on the use of disability data and a lack of disaggregated age data above 60 years old; no evidence on costs and benefits of different inclusion strategies; and little evidence on how disability and older age intersect and relate to gender, ethnicity and other identity characteristics.

Progress towards greater inclusion in the humanitarian sector has not escaped criticism. Our literature review found indications of 'inertia', or a tendency to continue to do the same things in the same ways as before rather than set ambitious new targets and innovate to achieve them. Despite important initiatives, including recent standards and guidelines, the need for greater inclusion of people with disability has been explicitly noted since at least the 1980s.[7] The sector is also criticised for prioritising people who are injured and may acquire a disability during a crisis rather than addressing disability inclusion more broadly.[8] Relatedly, the sector has been challenged for being driven by an outdated Medical Model, which stresses 'fixing' the individual, rather than a Social Model that emphasises barriers in society and a rights-based approach.[9] Understanding of older age has been criticised for lacking nuance, not distinguishing the diversity of lived experiences above 60 years of age, and for over-romanticising 'elders' and their influence in communities.



CLICK TO SEE FOOTNOTE REFERENCES (7 – 9) – PAGE 57

1.3 DISABILITY EVIDENCE MAPPING

TABLE 1. Mapping of disability articles by sector and humanitarian inclusion standards

	DATA COLLECTION & IDENTIFICATION	ACCESS TO HUMANITARIAN ASSISTANCE (INC. ACCESSIBILITY)	BUILDING PREPAREDNESS & RESILIENCE THROUGH HUMANITARIAN ACTION	MEANINGFUL PARTICIPATION	INCLUSIVE MECHANISMS FOR FEEDBACK & COMPLAINTS	COORDINATION OF INCLUSIVE HUMANITARIAN ASSISTANCE	ORGANISATIONAL LEARNING FOR INCLUSIVE HUMANITARIAN ASSISTANCE	STAFF & CAPACITY FOR INCLUSIVE HUMANITARIAN ASSISTANCE	MANAGING RESOURCES FOR INCLUSIVE HUMANITARIAN ASSISTANCE
CAMP MANAGEMENT		1			1				
COMMUNICATIONS	1	5		1	1		1	3	1
HEALTH	1	4				1	3	1	3
PROTECTION		3					2	1	
SHELTER	2	1					2		1
WASH		1							
GENERAL	2	4		1			1	1	

1.4 OLDER AGE EVIDENCE MAPPING

TABLE 2. Mapping of older age articles by sector and humanitarian inclusion standards

	DATA COLLECTION & IDENTIFICATION	ACCESS TO HUMANITARIAN ASSISTANCE (INC. ACCESSIBILITY)	BUILDING PREPAREDNESS & RESILIENCE THROUGH HUMANITARIAN ACTION	MEANINGFUL PARTICIPATION	INCLUSIVE MECHANISMS FOR FEEDBACK & COMPLAINTS	COORDINATION OF INCLUSIVE HUMANITARIAN ASSISTANCE	ORGANISATIONAL LEARNING FOR INCLUSIVE HUMANITARIAN ASSISTANCE	STAFF & CAPACITY FOR INCLUSIVE HUMANITARIAN ASSISTANCE	MANAGING RESOURCES FOR INCLUSIVE HUMANITARIAN ASSISTANCE
CAMP MANAGEMENT		4							
COMMUNICATIONS		2						1	
FOOD SECURITY	1								
HEALTH	1					1			1
LOGISTICS		1							
SHELTER		1						1	4
WASH		1							
GENERAL	1	6				1			1

2.0

APPROACH

2.0 APPROACH

Findings from the literature review only provide part of the story about how policy, guidelines and standards influence practice in humanitarian response. **Part 2 of the Gap Analysis aimed to provide an understanding of how available evidence leads to better inclusion of people with disability and older people in humanitarian response, and what are the barriers to effective uptake of evidence and good practice in real-world situations.** To address this aim, data was collected from interviews, an in-country consultation workshop, and online stakeholder workshops with humanitarian actors and disability and older age advocates. The findings strengthen the Gap Analysis' contribution to evidence and help us to reflect on the implications of literature review findings for humanitarian practice.

Throughout the Gap Analysis, regular Steering Committee meetings provided valuable guidance on design, direction and approach. This included the finalisation of data collection tools, the prioritisation of respondent groups, and nominating potential participants.

2.0 DATA COLLECTION

2.1 INTERVIEWS

KIIs were the main data collection activity in Part 2 of the Gap Analysis. Qualitative KIIs were completed remotely via internet-based video or audio calls. Interview participants were humanitarian professionals, including those with and without a specific focus on disability or older age inclusion, and representatives of OPDs and OPAs (Table 3). The interviews were semi-structured to allow key topics to be explored and responses to be compared while leaving room for exploration of wider and emerging issues.

Interviews were completed by one of two researchers from the research team using a standard question guide. The research team developed the question guide, which included the main questions to ask different types of participants, and instructions on other questions to clarify or expand on answers provided. Question guide topics were finalised in consultation with the Steering Committee. Interviews lasted between about 40 and 80 minutes. Interviews were recorded to ensure there would be an accurate record for analysis. Each participant was asked for their permission to record the interviews before they decided whether or not to take part.

Ethics approval for the KIIs was provided by the Human Ethics Sub-Committee of the Faculty of Medicine and Dentistry, University of Melbourne.[10]

2.2 COUNTRY CONSULTATIONS

Consultations with people with disability and older people who had experienced humanitarian response were originally planned as part of the Gap Analysis method. The consultations were planned to be held in Indonesia, Pakistan, Malawi, and Tonga. In February 2020, ASB facilitated the consultation in Indonesia. Subsequent travel restrictions and safety concerns due to the COVID-19 pandemic meant that the remaining three in-country consultations could not go ahead.

The Indonesia consultation was held in Semarang, Central Java with additional participants from Sulawesi. It focused on responses to natural hazard emergencies including earthquakes, tsunami, floods, volcanic eruptions, and landslides. Focus group discussions were facilitated by ASB, with people with disability in Indonesian language and with older people largely in Javanese language. Question guides were designed in advance by the researchers and ASB team to explore prior experiences of response, what worked and did not during the response, and priorities for improving future response. Reasonable accommodation was provided, and a qualified psychologist was on hand in case any participants experienced any distress when recalling past experiences.

2.3 ONLINE WORKSHOPS

Three online workshops were conducted to ensure that findings were discussed and shared with a diverse group of stakeholders. The aim of these workshops was to assist in interpreting findings, refining our conclusions, and in making relevant and practical recommendations.

The workshops followed the same format and addressed the same content. They were held across three different time zones to allow global participation. The number of attendees was deliberately kept small, at around 20 people per workshop, to encourage active participation by those involved. The online workshops discussed key findings from the literature review, with small group discussions focused on one of three emerging themes also identified in the KIIs: organisational change, data, and intersectionality. Closed captioning and the option of providing questions and comments by text was provided.

CLICK TO SEE FOOTNOTE REFERENCE (10) – PAGE 57

2.4 PARTICIPANT SELECTION – INTERVIEWS

For the KIIs, potential participants were identified in collaboration with the Steering Committee. Inclusion criteria included having direct knowledge or experience of humanitarian response; having participants from a range of geographical regions; having a balance of gender; and ensuring representation from humanitarian organisations, OPDs, and OPAs (see section 2.7 below on limitations). Steering Committee members suggested possible respondents from their professional networks and the researchers selected the list of people to be invited for interview. The final selection was completed in confidence. No names or other identifying information of the people interviewed were shared with the Steering Committee.

Potential interview participants were sent a standard email invitation, including a plain language statement explaining the purpose of the research, why the person had been selected to be invited, and use of information and confidentiality. If there was no response, one email reminder was sent. If there was still no response following the reminder, the researchers did not contact the potential participant again. **Table 1** describes the broader characteristics of the interview participants.

TABLE 3. Key informant characteristics

CATEGORY		NUMBER OF KIIs
REGION	AFRICA	3
	AMERICAS	1
	EUROPE	1
	GLOBAL	6
	OCEANIA	3
	SOUTH ASIA	3
	SOUTH EAST ASIA	3
GENDER	FEMALE	12
	MALE	8
SECTOR[11]	AGEING	4
	DISABILITY / AGEING	2
	DISABILITY	7
	MAINSTREAM	5
	OPD REPRESENTATIVE	2

CLICK TO SEE FOOTNOTE REFERENCE (11) – PAGE 57

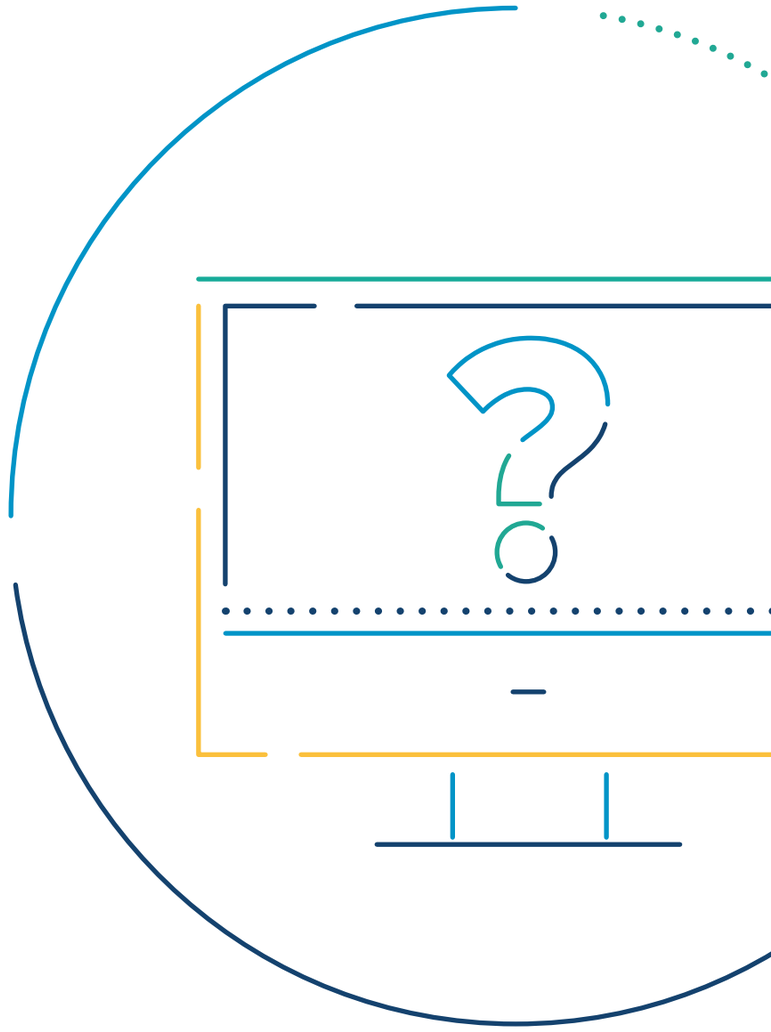
2.5 PARTICIPANT SELECTION – CONSULTATIONS AND ONLINE WORKSHOPS

Participants for the consultation in Indonesia were selected by ASB according to criteria agreed with the researchers. Criteria included a balance of gender, a range of impairment types for people with disability, and experience of an emergency or disaster involving a response.

Plain language statements in Indonesian language were provided to potential participants in advance. This included verbal clarification, including in Javanese language as appropriate. Verbal consent to participate was obtained in advance and again before the start of the consultation. Specific accessibility and travel requirements were identified and arranged in advance. Each participant received a small financial contribution to cover any additional costs of participation. Six older people and eight people with disability with physical or sensory impairments participated in the focus groups.

Invitations to online workshops targeted specific groups identified by the Steering Committee. These included disability stakeholder groups and OPDs working on humanitarian response, organisations focused on older age inclusion and OPAs, and humanitarian organisations. From these groups, participants self-selected to register and take part. Places on each of the three workshops were limited and were quickly filled.

The researchers assigned a small number of additional participants who had expressed interest in the workshops. These included participants from local government civil protection teams. Individuals from humanitarian organisations that had expressed interest but were not able to take part in interviews were also invited by the researchers. A total of 61 people participated in the online workshops.



2.6 ANALYSIS OF DATA

After each KII, full transcripts from the audio recordings were prepared. These transcripts were entered into software (NVivo) to help organise the transcript texts for analysis. Based on the question guides, we developed a list of themes and sub-topics (codes) for thematic analysis. Themes included the types of information in use, how information is used, and barriers and enablers to using the information. The two researchers leading the interviews reviewed a sample of interviews against these themes. This led to the identification of new, or emerging, themes and sub-topics.

As the interviews were analysed, new themes emerged. These 'emergent' themes are important in understanding the real-world experiences of interview participants and in interpreting findings. The researchers adjusted themes and sub-topics during subsequent review and analysis. The researchers emphasised how findings from the KIIs were related to, and provided context for, the literature review findings.

After a preliminary analysis, some key findings from both the literature review and KIIs were presented and discussed with online workshop participants. Three emerging topics from the Gap Analysis were presented for discussion in smaller working groups during each workshop. These topics included: **organisational change, data,** and **intersectionality**. Organisational change and data were both identified as issues during the literature review and by individuals in KIIs. Inputs from workshop participants allowed us to identify common issues across organisations and understand the context for KII findings. It was clear from the workshops that data was a cross-cutting concern for participants as it was discussed in multiple working groups.

Gaps in evidence on intersectionality emerged from the literature review but were not explored in detail during the KIIs. The online workshops allowed us to discuss intersectionality further, particularly between disability and older age. The workshops confirmed that intersectionality is an area of interest and concern across different organisations. This is discussed further in Section B.

2.7 ISSUES AND LIMITATIONS

During the Gap Analysis we encountered a number of issues and limitations that should be kept in mind when considering the findings and recommendations.

While the Steering Committee and researchers were able to identify OPDs with experience of working in humanitarian response, it was harder to identify OPAs with this experience. This imbalance was also reflected in membership of the Steering Committee and was a point of reflection for both the Steering Committee and researchers throughout the Gap Analysis.

The limited number of OPAs working in response meant we needed to draw on representatives of NGOs focusing on older age in interviews and online workshops. However, the number of these organisations with humanitarian experience is limited. For the Indonesia consultations, identification of OPDs to participate or to suggest participants was relatively straightforward, whereas identification of older people was more challenging due to a lack of similar formal organisations of older people.

The cancellation of in-country consultations due to COVID-19 restrictions meant that **the participation of people with disability and older people who had experienced a humanitarian response in the Gap Analysis was very limited.**

Alternative options were discussed with OPD and/or OPA partners in the target countries. This included the possibility of in-country partners conducting interviews or arranging remote interviews. All options would have involved contact in some form with potential respondents, including arranging the logistics of remote interviews and ensuring access to technology. As the COVID-19 pandemic was emerging there was uncertainty and all alternative options were considered too high-risk at that time.

The Indonesia consultation focused on responses to natural hazard emergencies. The consultations planned in Pakistan, Malawi, and Tonga would have addressed experiences arising from conflict, hazard-related disaster, and a health emergency respectively but were not able to go ahead.

KIIs also coincided with the COVID-19 pandemic. With humanitarian organisations having to adjust their work and respond to the pandemic, some potential participants declined to be interviewed. Where possible we tried to identify alternative participants in line with our original inclusion criteria. We interviewed 20 people in total. The number of interviews was considered to have reached saturation, meaning that limited extra information would be gained from additional interviews. Interviews and online workshops were conducted in English language.

B

SECTION B

FINDINGS

3.0

KEY THEMES

3.1 SETTING THE AGENDA

There is good awareness of global commitments to inclusion in humanitarian response, including the Sendai Framework and the Charter, alongside broader commitments in the 2030 Agenda and Sustainable Development Goals (SDGs).[12] These frameworks and commitments have effectively set an ambitious agenda for inclusion. Disability-focused respondents noted the importance of the CRPD and that its principles are universally applicable across response. There is also awareness of related standards and guidelines among humanitarian professionals. The publication of the IASC guidelines was seen as providing further credibility and traction within the UN system and with donors, as the IASC guidelines are hard 'to shy away from.'

The CRPD and commitments to inclusion in international frameworks were acknowledged as being important for advocating the inclusion of people with disability and older people in humanitarian response. It was also noted that the need for advocacy is ongoing. For disability and older age advocates, the HIS and IASC guidelines help to raise awareness further and to get a 'seat at the table'. One participant noted that when providing advice during response, the standards and guidance are a 'reminder of what needs to be done' and create 'opportunities for questions if they ['mainstream' humanitarian actors] are not clear in a particular area'. As another noted, guidance is something 'we [disability-focused organisations] request [generalist] organisation[s] to adhere to'. Another commented:

> 'It's fascinating in [the] last two and a half to three years how much demand has come from mainstream humanitarian agencies seeking support to make their work inclusive.'

Stronger and increasingly 'binding' principles support and raise the voice of advocacy and ensure other actors take notice of advocacy messaging. At the same time, frameworks create obligations through minimum standards and donor requirements. One workshop participant described it as 'the international clamour for inclusion'. While donors were noted as a positive driver of inclusion currently, it was cautioned that if donors stop prioritising inclusion then implementing organisations may follow. The cascading impact of frameworks was also noted in interviews. The availability of national and sub-national policies addressing inclusion was considered important for establishing expectations and setting standards during response. It was noted that **in some humanitarian responses OPDs were becoming more assertive and were further driving inclusion.**

Overall, we found that global commitments to inclusion are well-known and that standards and guidelines are further contributing to raising the profile of the inclusion of people with disability and older people within the humanitarian sector.

CLICK TO SEE FOOTNOTE REFERENCE (12) – PAGE 57

3.2 TRANSLATING COMMITMENTS INTO PRACTICE

The most frequently used sources of evidence and information mentioned in interviews were recent guidelines and standards. One of the purposes of these standards and guidelines is to provide answers on 'how' commitments to inclusion are translated into practice. This includes closing knowledge gaps to ensure inclusive approaches are implemented well. This section outlines how guidance and standards are impacting organisations' work and how they are being used.

Having more guidelines and norms to draw on has been very positive overall, but having multiple documents to be familiar with and put into practice is a significant challenge. Online workshop participants voiced concern that the number of guidelines that humanitarian professionals are expected to be familiar with can be overwhelming.

One online workshop participant noted:

- 'The IASC [disability] guidelines are over 150 pages and then we have guidelines for gender, gender-based violence, and so on'.

PERSON WITH DISABILITY, MALE. INDONESIA.

SNAPSHOT: STORY OF A CONSULTATION PARTICIPANT

I guess I was lucky because I only have a mild physical disability, so I didn't experience what my other friends with disability experienced. When the earthquake and tsunami struck, they were left behind by their families. Seeing this situation, I volunteered to coordinate a command post for people with disability together with some other friends who also have a disability. I did that because I see that people with disability are forgotten. And as a person with disability, I feel that it is easier for me to relate to other people with disability, including their specific needs.

I tried to inform the Social Welfare Department about the locations of people with disability that I knew of. The Social Welfare Department offered those of us who survived to shelter at their office. But we did not go. There is no accessible toilet there, so I figured it would be very challenging for my friends. The Social Welfare Department then suggested we get food items from them, but we only went there once. The next day we did not go because there was no gasoline.

I stayed for two weeks at the evacuation site. It was very challenging because there was no access to water. I'm the only one with a mild disability, so I could help my friends to get water from the well. I did not feel supported in my role at the command post for people with disability. When we received assistance only for people with disability, such as food distributions, often other people without disability envied us. So it was a very difficult situation for us.

3.2 TRANSLATING COMMITMENTS INTO PRACTICE

The content of high-level guidance was considered to be of good quality; however, the challenges of communicating this content were noted:

- 'The big big documents that were developed, they're very good. But you know, in [this country] people don't read a lot.'

- 'We do try to summarise, simplify, translate, but the original ones are quite a challenge. This is a challenge - a significant problem. I don't know how much I would weigh it against other problems, I believe these are excellent resources, so if there were shorter and simpler versions, it would make a big difference.'

Several participants described that while these guiding documents have made inclusion a core part of the agenda, they still require 'champions' with voice and 'personal connections' to ensure guidance is taken up.

'There are a lot of very good documents by now. For me it's more you need human anchoring of this knowledge in a crisis, you need multipliers who can carry it.'

It was also noted that work remains to be done to ensure standards and guidance are consistently understood and used, including within inclusion-focused organisations:

- 'I can say that all those [high-level] documents are sources that we refer to but we are still trying to promote them at the same time. […] All these documents are there but not all [our] missions, not everywhere - they are not used very much everywhere.'

Several respondents described how they used standards and guidelines to inform training for staff. It was also notable that 'mainstream' humanitarian organisations are now developing their own in-house training on the inclusion both of people with disability and of older people. One respondent working in a large mainstream organisation shared that standards and other guidance are 'embedded' in their training. Another respondent reflected that while inclusion guidance and tools were aimed at being used practically in a response, they also had the benefit of generating discussion and reflection on how inclusive their organisation's responses were.

3.2 TRANSLATING COMMITMENTS INTO PRACTICE

We found that high-level guidance is a common source of information on the inclusion of people with disability and older people for humanitarian actors. It is also clear that these sources of information are contributing to raising awareness and are being applied to improve understanding of disability and older age inclusion in general.

However, from overall Gap Analysis findings it is less clear that available high-level standards and guidance are contributing to improved inclusion in practice. As one respondent noted:

- '[The HIS are] I mean really light […]. Very general […]. For specific sectors, you need specific tools and adaptations - those are not provided in the HIS.'

Although interview respondents noted a lack of sector-specific information overall, there were exceptions. These included All Under One Roof: Disability-Inclusive Shelter and Settlements in Emergencies, 2018 and individual guidance on nutrition, health and education from UNICEF, 2017.[13,14] Respondents working at the intersection of gender and disability rights noted the availability of documents addressing gender-based violence.[15]

Overall, participants did not feel there was a gap in the availability of general guidance on disability and older age inclusion. For example, one participant said:

'most guidance we could need, to a large extent, exists'.

Another echoed that 'plenty [of guidance] exists'. The common theme was that high-level guidance and standards 'put [inclusion] on the table but are not really useful' in terms of informing what humanitarian actors need to do. **Respondents told us that more sector-specific technical information is required.** Further, translating guidance into practice requires resources, contextualisation, and the desire for change. These and related issues are discussed later.

CLICK TO SEE FOOTNOTE REFERENCES (13 – 15) – PAGE 57

3.3 ADOPTION OF GUIDANCE

We found that the adoption and uptake of information and guidance varies within and between organisations. Interview and workshop participants noted various factors that could influence the extent to which organisations build inclusion into their work. **The need to better understand what may enable or prevent organisations from adopting guidance and becoming more inclusive was evident in both the literature review and interviews.**

Interview participants highlighted that while there is enough general guidance on the inclusion of people with disability and older people in humanitarian response, the uptake and application of this guidance is often missing or delayed within organisations. Participants in online workshops noted a tendency for organisations to 'fall back on what they know'. For example, if an organisation has a focus on gender, it is unlikely that it will 'shift' to disability inclusion when a rapid response is required.

Workshop participants noted:

'We remain siloed and rather than break down the walls of these silos we shift between them.'

- 'There's been a lot of progress in mainstreaming inclusion more broadly. Less so in response. It's like in an emergency, we focus on ourselves and our own family before we help our neighbours. Organisations act like this in a disaster - they stick to their main focus area.'

Participants in the online workshops also noted that the progress of change towards increased inclusion is uneven. While progress was being made by disability and older age-focused organisations in improving inclusion in response, there was less progress by 'mainstream' organisations. An OPD participant noted that while they are increasingly considering gender in their work, older age has received less attention.

It was also noted that the inclusion of people with disability and older people is sometimes left to later stages of a response. Falling back on what is known and what is familiar to organisations can result in the exclusion of people with disability and older people in the critical early stages of rapid responses. While there was recognition that inclusion should be addressed before a disaster or a response, it was also noted that guidance on preparedness tends to oversimplify what happens in reality.

- 'We need to consider different points of entry. The reality is: proposals in response are submitted quickly - they may be written out of country at headquarters. Then they are adapted and changed as the response unfolds. So, there is not one point of entry. We have to consider where we can add, and budget for, [inclusion] activities at different points as programmes [are developed during the] response.'

3.4 ADAPTING GUIDANCE TO DIFFERENT CONTEXTS

Previous sections have described how 'high-level' guidance is used to set a broad agenda, but that the right enablers are required to drive the uptake and implementation of guidance. Another important gap identified was the need to adapt guidance to different humanitarian contexts. One respondent outlined a perceived gap, especially in guiding local decisions about programming and resource allocation:

- 'There's [no guidance] in the 'middle'… at the level of the emergency operation centre, for example, where decisions are being made, where resources are sort of decided on where to be deployed… there's no document [about inclusion] at that level.'

Contextual factors that influence the type of response might include the type of hazard or crisis, population demographics and identity characteristics, local political conditions, and the length and scope of the response. One respondent reflected on the amount of time it takes for collaborating partners to engage with contextualised information:

- 'That requires time. If it's a natural hazard [emergency], that time is lost because it's a fast pace and in seven to eight months the first response will be over. What we are seeing in a protracted crisis [is] we are seeing the first eight months is setting a base for partners to understand the diversity involved and the nuances they will need to engage with to tailor their response to be more inclusive.'

One respondent explained that their organisation had worked to combine guidance, local laws and good practice into a specific, step-by-step 'manual', to be used in response. This was possible and necessary because she was working in a country with a very high frequency of large-scale emergencies. It was also helped by close engagement with government authorities through formal coordination mechanisms. The higher-level information is there as a backup or reference to provide overall direction:

- 'The only thing that I have [at the time of early assessments in a response] is the manual that has the response plan and anything that is in my bag I'm going around with - I didn't really like look at it every time. It's just when I'm in meetings. I just flip through, just make sure that I have my head right.'

These findings are reflective of a gap in the process of adapting guidance. **There is greater emphasis on the *products* or *outputs*. That is: what resources and materials are available and used, and whether responses are inclusive. There is less awareness and fostering of a process of adapting and refining good practice to the time and place of a particular response.** Doing so is complex. As one participant put it, this process:

- 'Calls for synergy of what [local government actors] want to implement and what we want to implement, so that we can work as a team at the end of the day. This may not be followed fully, based on the locality, the government and, of course, based on the restrictions or regulations when it comes to implementing in certain areas.'

3.5 THE INTERSECTION OF DISABILITY AND OLDER AGE

Our literature review looked at the evidence for disability and older age separately. This was to ensure a wide search for literature on both disability and older age. It was clear that there is currently more literature that addresses disability inclusion in humanitarian response compared to the inclusion of older people. We also identified **little evidence that directly addressed the links, or intersectionality, between disability and older age**, as well as other identity characteristics, such as gender, religion and ethnicity. Findings from interviews and the online workshops indicate that progress on the inclusion of older people lags behind the inclusion of people with disability in humanitarian response.

People face a decline in their ability to function in older age. For example, reduced mobility, vision or hearing. As such, there are similarities with disability in terms of the need to address accessibility requirements, including the availability and use of assistive products. There is also the concern that functional limitations will be more severe for older people with disability, which can increase the levels of risk individuals experience over time.

OLDER PERSON, FEMALE. INDONESIA.

SNAPSHOT: STORY OF A CONSULTATION PARTICIPANT

The situation in the evacuation centre was uncomfortable because there was a mix of children, older people, men and women - everyone. Sometimes it was hard for me to get any rest or sleep because it was too noisy. The situation affected my health and it got worse for me because there were other evacuees there who were sick and I worried that it would spread to me.

3.5 THE INTERSECTION OF DISABILITY AND OLDER AGE

Although more organisations are collecting disability data in humanitarian response, largely using the Washington Group questions, progress on improving the collection of older age data seems to have stalled. In interviews there was acknowledgment of the diversity of disability and related needs. However, the literature and workshop participants suggested that women and men over 60 years old still tend to be grouped together. **There is little consideration of differences between the young-old, middle-old or old-old above 60 years of age.** Understanding functional difficulties and access needs by 10-year age groupings and gender may assist in ensuring more targeted and more appropriate responses.

A key finding from both the literature review and interviews is the need for more nuanced understanding to guide practice at the intersection of disability and older age. While there are linkages between disability and older age, there are also differences. Due to stigma or individual prejudices, some older people may not wish to be directly associated with people with disability. The needs of a younger person with a particular impairment may be very different from those of an older person with the same impairment. Importantly, older people may not self-identify as having a disability.

Identifying as being a person with disability has been central to the disability rights movement and has allowed collective organisation and action. During the Gap Analysis we, and the Steering Committee, found it difficult to identify OPAs with experience of humanitarian response. We had comparatively less difficulty in identifying OPDs with experience of response. This may well be mirrored in humanitarian response settings.

3.5 THE INTERSECTION OF DISABILITY AND OLDER AGE

DISCUSSION POINT

Older people and disability inclusion: two observations from experts

By talking to stakeholders in both disability inclusion and older age inclusion sectors, we were able to understand different viewpoints on how the two sectors are complementary. We also noted several challenges and sensitivities.

On the one hand, working with older people can be an effective means for wider community development as the voice and experiences of older people can be important in shaping community attitudes. One interview participant told us:

- 'We always advocate, emphasise inclusion of older people not only for their benefit but for the community in which older people perform important roles. Older people's leadership is an entry point for community development. That's not well understood by groups, small ones but also the big ones like big donors, like EU or World Bank.'

However, as identified in our literatue review, there is the risk of overromanticising older age and overestimating the influence older people may have. When we discussed preliminary findings in the online workshops, one participant described their own experience as a person with a disability. They said:

- 'Older people can sometimes have outdated and prejudiced views. In [my country] for example, many if not most older people still hold beliefs about disability arising from a curse and sins in a past life. [In an emergency camp scenario] they did not want to share the camp with disabled people.'

These experiences and expertise highlight some important challenges in working across sectors, and the potential value in cross-sectoral sharing of lessons learned and good practice.

3.5 THE INTERSECTION OF DISABILITY AND OLDER AGE

DISCUSSION POINT

Consultation in Indonesia: the voices of people with disability and older people

The consultation in Indonesia included focus group discussions with people with disability and older people who had experienced a response to a natural hazard emergency. The discussions identified both common and distinct priorities for the two groups.

For example, both groups noted the need for more accessible and clearer information, including being kept informed of any changes in the hazard alert status, evacuation procedures and locations, and information on relief distributions. The importance of people with disability not being separated from a carer, and older people not being separated from family members in shelters, were both ranked highly. Other shared considerations included providing assistance for moving to shelters and ensuring the availability of medical services at shelters. However, priorities also differed between the two groups.

Participants with disability tended to prioritise access. This included ensuring distribution sites were accessible, or assistance could be delivered directly to people with disability. The importance of including OPDs in response was also noted. The need for training and for equipping shelter personnel to better understand access needs and to provide reasonable accomodation was also recognised.

Older people shared concerns over access and also noted that being in shelters with people of all ages made it difficult to rest and it increased stress. However, priorities for older participants largely related to livelihoods. This included the importance of being able to evacuate with, and provide shelter for, livestock. Concerns over the security of homes and property while they evacuated was noted. Older people also noted that they should be included in cash-for-work schemes - not only for financial reasons but also to ward off boredom.

There are merits to an approach that considers improving the inclusion of both people with disability and older people in response. At the same time, the diversity of both disability and older age and the specific needs of individuals should not be overlooked. On a broad level, both groups in the consultation in Indonesia had the same concerns:

Do not ignore us. Keep us informed, consult with us and include us.

4.0

CHALLENGES

4.1 SHIFTING PRIORITIES AND CHANGING ATTITUDES

While frameworks, guidance and standards are contributing an enabling environment for the increased inclusion of people with disability and older people in humanitarian response, these have not been internalised within all organisations. As noted above, adoption of guidance has been mixed. The following sections describe some of the challenges.

During the online workshops, the need for high-level buy-in and senior management support within organisations was noted. Without this, the potential for organisations to internalise guidance, try new approaches, and learn from mistakes appears limited. **Leadership was considered essential to ensure inclusion is prioritised and not overlooked**, particularly during the early stages of response. Relatedly, in interviews it was noted that current guidance is largely aimed at responder teams and that there is limited information targeted at senior emergency response managers or incident command personnel.

PERSON WITH DISABILITY, FEMALE. INDONESIA.

SNAPSHOT: STORY OF A CONSULTATION PARTICIPANT

When the water came into our house, it was already knee-high. I live alone with my mother - she is an older person who is using crutches. I use a wheelchair. I did not know how we would manage to evacuate. Eventually, we managed to get out. I went to my neighbour's house, together with my mother, and we stayed there for a night before moving to the evacuation site. My house was only made of plywood - it fell apart.

We were so cold. The dirty water made me feel itchy. I couldn't sleep, and I'm sure that is why I got high blood pressure. At the evacuation site, I couldn't use the toilet. I could not shower. I could only stay in bed the whole time and I could only use wet tissues to clean myself. Nobody accompanied or assisted me, there was only my mother.

4.1 SHIFTING PRIORITIES AND CHANGING ATTITUDES

Workshop and interview participants reported that attitudinal barriers were a challenge. One disability advocate expressed frustration at the amount of time still needed to get initial 'buy-in' for disability inclusion from humanitarian organisations before they could start working on changing systems and approaches. An interview participant reflected criticisms from the literature review that the sector can prioritise the injured, who may acquire an impairment, over broader disability inclusion:

- '[Mainstream humanitarian organisations] have their so-called priorities of saving lives. So, how do you now incorporate disability inclusion issues within those types of discussions?'

One workshop identified fear of addressing disability within organisations as a challenge. As a workshop participant reflected, being unsure of what needs to be done can be a barrier to change:

'individuals and organisations are worried that working on disability can be opening up a can of worms.'

Further, just as strong advocates and 'champions' are facilitators and enablers of greater emphasis on disability and older age inclusion, people can also act as barriers. For example, administrative changes and the rotation of government officials can disrupt positive efforts and progress towards inclusion. One participant reflected:

- 'When you have a change in administration, that's a very big problem. Because before, we were able to get a [budget from local government for inclusion]. But with this new administration, we cannot get through. We cannot even conduct a courtesy call [to share our] remarkable programme on disaster risk reduction.'

4.2 MOVING BEYOND ENGAGEMENT

Efforts to 'engage' with people with disability and older people were reported in interviews. However, it was noted that engagement often fell short of ensuring meaningful participation.

The importance of ensuring people with disability and older people are equipped to participate was noted as being central to inclusive response.

> 'You know, if those local DPOs are not working with the local emergency managers, then almost nothing else matters. If the humanitarian organisations aren't working with disability-led organisations on an equal footing, that is a very clear indication that there is no inclusion.'

It was noted that, to be meaningful, **participation needs to go beyond asking people with disability and older people about their 'needs' or just inviting them to attend meetings and consultations.** There needs to be conscious efforts to involve people with disability and older people in decision-making at all stages of humanitarian programming. One disability-focused respondent commented that engagement with OPDs during preparedness in advance of an emergency should be an indicator for inclusion. Another reflected that inviting people with disability and older people to participate is not enough and, alone, could even be damaging.

- 'We can invite [people with disability] but if they don't understand what the system is, you know, they don't understand what the incident command system is, and how response is being done […] you're just marginalising their participation.'

Examples exist of people with disability being equipped to contribute directly to response. It was noted that the process of capacity building needed time and resources. Also, that available guidance may not be accessible or understandable.

4.2 MOVING BEYOND ENGAGEMENT

- ‘Most persons with disabilities in the Pacific, they do not go to school - we need to take it down another level. […] For most responders with disabilities we need to sit with them […] to ensure that the capacity is built to understand how the humanitarian system works and what are the humanitarian processes. Understanding that and then [being] able to identify their entry points in that [is important] for [people with disability] to effectively share their lived experiences and represent their voice in the humanitarian space.’

References to capacity development in interviews were not only directed towards OPDs and OPAs. One participant noted the importance of developing the capacity of local government agencies, that are responsible for response, on inclusion. The participant noted that developing local government capacity could also improve local ownership and implementation of inclusive humanitarian action rather than responses being driven by external agencies. The concern was that local government officials and mechanisms with responsibility for the inclusion of people with disability and older people can be overlooked, rather than equipped to contribute to humanitarian responses.

OLDER PERSON, MALE. INDONESIA.

SNAPSHOT: STORY OF A CONSULTATION PARTICIPANT

When the volcano erupted, people from my village, including me, only stayed for three days in the evacuation centre. This was because we were thinking about the condition of our livestock - especially the cows and goats which we left behind in our village. There was no place for our livestock near the evacuation centre.

The condition of the evacuation centre was also uncomfortable for me due to uncleanliness of the environment and the lack of enough toilet facilities. We decided to move and stay at another village that provided some place for our livestock and provided a ‘host family’ for us to stay with - with sufficient water and toilet facilities. Now my village government has formalised a collaboration with the other village as a host village in preparedness for future evacuations.

4.3 SHARING OF PRACTICE AND TECHNICAL ASSISTANCE

In interviews and online workshops, there was the view that existing inclusion guidance could be better aligned and integrated with other thematic guidance, such as on gender.

It was noted that learning from the experiences of other organisations and sharing examples of good practice could be helpful, particularly when there are limited resources and it is not possible to employ a dedicated inclusion advisor. However, it should be noted that good practice compilations do already exist.[16] **Alternative formal and informal mechanisms for sharing of experiences and learning between humanitarian professionals may be beneficial.** As one interview participant noted:

- 'Sometimes organisations don't have the time to think and would value [knowing] what other organisations have done to become inclusive.'

Our literature review noted that disability inclusion can be perceived as the responsibility of specialist agencies or, as indicated above, external experts and advisors. Similarly, interview participants noted that the availability, or lack of, staff with expertise and designated responsibilities can impact on inclusion efforts:

- '[It's] very much dependent on individual personalities at the moment, especially when you are deployed [to a country]. For example, I could go in and I can be like: oh well, I am not an expert on disability, it's not my area. I just need to make sure that the project goes really well, you know. I will just make sure that I am not leaving anyone behind - but what does that mean? It's very, very subjective.'

CLICK TO SEE FOOTNOTE REFERENCE (16) – PAGE 57

4.4 BUDGETING FOR INCLUSION

The importance of allocating funds to implement guidance was noted, both in interviews and workshops. This included for reasonable accommodation to facilitate participation in response activities, producing accessible materials, and for including representative organisations of people with disability and older people in decision making. As one respondent noted:

- 'I think the missing piece is the resources. That's the missing piece. There's a lot of guidance out there around disability inclusion. But there's no money to build the capacity of persons with disabilities and organisations of persons with disabilities to ensure accountability of state parties, or for duty bearers.

> I think for me, the biggest gap within the sector is the resources that are [not allocated] towards disability and knowledge sharing.'

'Mainstream' organisations were also criticised for underestimating costs and not allocating sufficient budgets for implementing guidance. This included not having dedicated and specific budget lines in programme and activity budgets. One disability-focused participant noted their organisation allocates around 10% to 20%, depending on the location and context, of every project budget towards accessibility and inclusion. Another complained that, at times, 'mainstream' organisations expect disability-focused organisations to provide accessibility on their behalf, such as providing sign interpreters as a 'voluntary contribution' to the response. A related issue to the allocation of resources was data, which is discussed further on the following pages.

4.5 COLLECTING AND USING DATA

Issues of data were raised across the Gap Analysis. The need for data disaggregated by disability and age was acknowledged in interviews and in online workshops. However, the collection and use of data and the availability and appropriateness of tools present challenges.

Prioritisation and the allocation of resources was directly linked to having data on disability and older age. As one interview participant commented:

- 'Well I think data is absolutely essential because without it, resourcing is impossible, right? It comes with a cost. Not just costs and money into pockets, but investment in capacity in order to do inclusive programming- and that will need investment in programming.'

There were also concerns that despite awareness of the need for disaggregated data, the collection of such data was still not prioritised. Another participant noted that disability data is not always included in humanitarian response reports and that data on age is not always disaggregated. For some, this was a fundamental problem:

- 'The simplest problem is institutions don't think there is a need for disaggregated data

That's one issue - the most important issue. Disaggregated data collection allows understanding of specific problems of different people and when organisations fail to collect disaggregated data, they normally fail to address the need for inclusion.'

A number of sources of data were identified in interviews. These included existing government survey or census data, OPD registries and membership lists, cluster team reports and snapshots. It was also noted that humanitarian actors should check with local organisations and networks. It was further noted that while secondary data may be all that is available, it may be out-of-date or inaccurate. However, secondary data was considered a good starting point when primary data cannot be collected immediately.

- 'Oftentimes we underestimate the information that already exists in the country and the community through the existing systems. The ministry already captured a lot of information about disabilities. There were programmes that had done community mappings [...].'

4.5 COLLECTING AND USING DATA

While collecting primary data was noted as preferable, it could also be challenging. One interview participant noted that data collected from households or in camp settings during response would often be inaccurate.

In interviews, the Washington Group questions on disability were recognised as an available tool for identifying people with disability.[17] However, use of the Washington Group questions was considered time-consuming and their effectiveness largely dependent on how well data collectors are trained. In the literature review we identified a small number of tools that have been used to identify access and functioning needs in response - largely from the shelter sector in the United States.[18] However these do not appear to be well-known in the wider humanitarian sector.

Missing people out in data collection, or not accurately capturing all people with a data collection tool, were noted as concerns:

- 'I have very mixed feelings about the disaggregation of data because it is so difficult to accurately get the data and I'm a person with a very significant disability. I have several very complicated health issues. […] So unless there was someone asking a question about, you know, do you have chronic health conditions? Unless you ask that question, I would never be counted. And I think there are far more people who are like me, than there are people for whom the answer to the question will be obvious.'

Collecting data does not provide value or strengthen inclusion if the data is not used appropriately. Across the Gap Analysis we identified few examples of the effective use of disaggregated disability and older age data. Also, the availability of data may not in itself lead to inclusion in response. As one interview participant reflected:

- 'Even when we have lots and lots of messaging that says, one in four adults has a disability, 26% of the population has a disability, and then we go on to say, you know your emergency preparedness planning needs to take into consideration the physical accessibility, programme accessibility, effective communication access needs of, you know, one quarter or more of your population. It still doesn't get done. So, if we had, if we had data, I don't know what that data would be - if we had, you know, specifics. I don't know what that would do to make things better, and I fear it would make them worse.'

CLICK TO SEE FOOTNOTE REFERENCE (17, 18) – PAGE 57

4.5 COLLECTING AND USING DATA

DISCUSSION POINT

Is collecting data about disability and older age being used as a 'proxy' for inclusion?

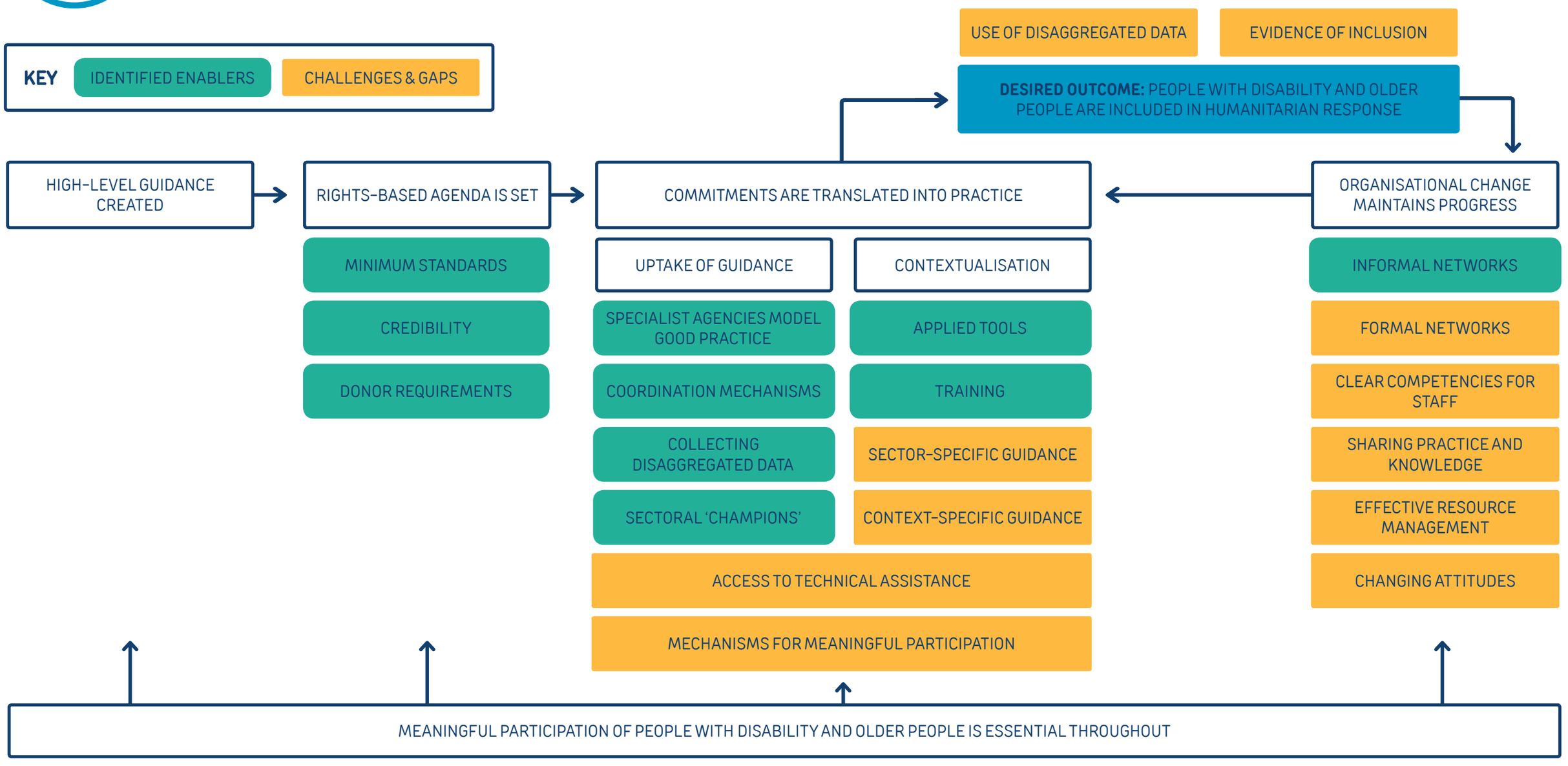
Perhaps the most prominent change in disability inclusive development and humanitarian action in the years since the CRPD has been the focus given to disability-disaggregated data. In the Gap Analysis, collecting data was described as a facilitator of resources and a pre-requisite for including at-risk people in responses.

While properly disaggregated data is clearly essential, there is some risk that the push for better data could have unexpected, negative consequences that are not usually discussed.

We learned that data about disability and age is often collected, but then not used to tailor responses to specific needs, even if there is a general better understanding about the proportion of beneficiaries who might experience disability and age ranges. Respondents described the time and costs involved in conducting thorough and robust assessments and their frustrations that data does not always inform practice.

This creates challenging questions for building on progress and defining methods for collecting information about disability and age in populations affected by crisis to ensure better data collection leads to direct impacts. Importantly, the collection of data should not be considered as a substitute for concerted actions towards improving inclusion.

5.0 HOW GUIDELINES AND CURRENT EVIDENCE CONTRIBUTE TO INCLUSIVE PRACTICE



This schematic illustrates how high-level guidance and current evidence contribute to inclusive practice, according to the Gap Analysis findings. Starting at the left, high-level guidance results in a rights-based agenda being set. With the right enablers, commitments are translated into practice and inclusion (the desired outcome) is achieved. The important role of organisational change in maintaining progress on inclusion is also highlighted (furthest right).

Throughout all stages, the meaningful participation of people with disability and older people is essential. Observed enablers of each stage are indicated in green (boxes with rounded edges), while observed challenges and gaps are indicated in yellow (boxes with squared edges).

SECTION C

LOOKING AHEAD: IMPLICATIONS FOR INNOVATION AND PRACTICE

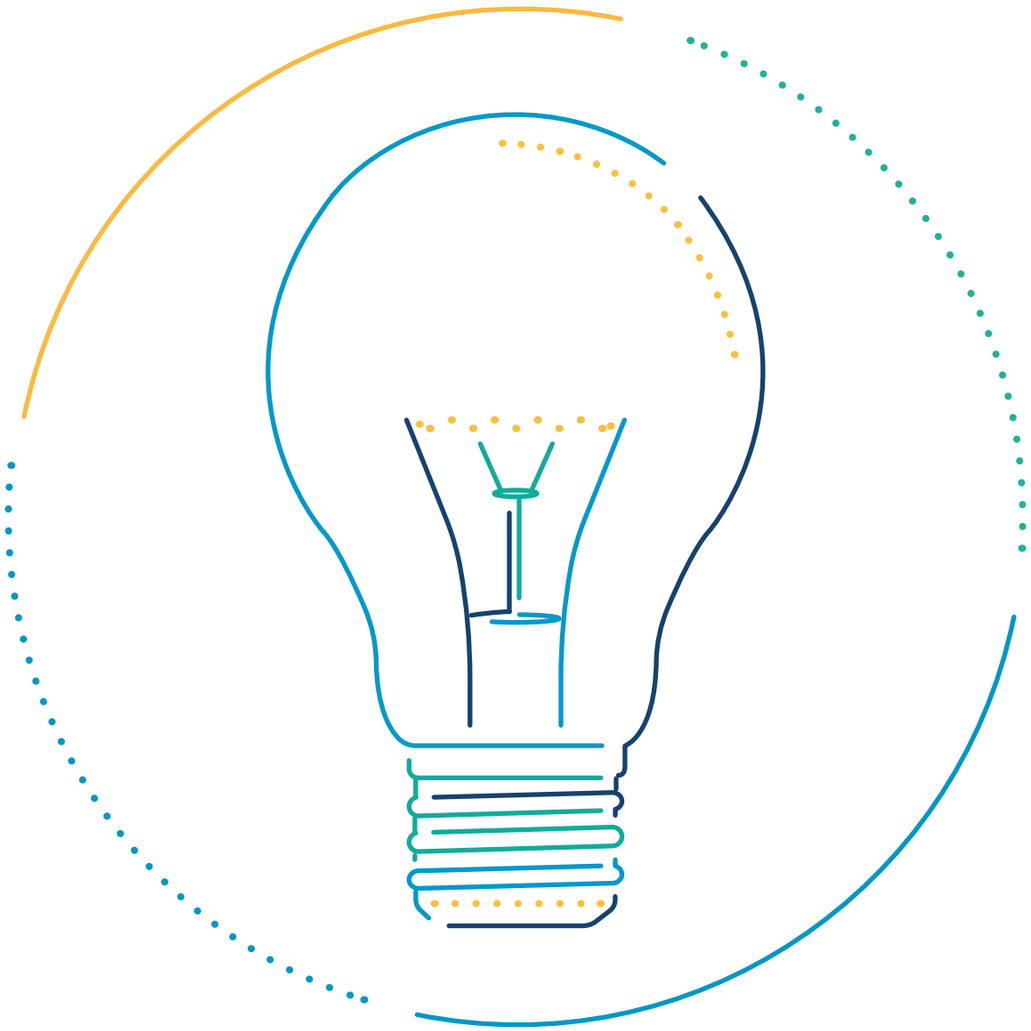
6.0

POTENTIAL AREAS FOR INNOVATION

6.0 POTENTIAL AREAS FOR INNOVATION

In this final section we bring together findings from Parts 1 and 2 of the Gap Analysis. We present below seven areas that hold potential for increasing the inclusion of people with disability and older people in humanitarian response. These areas contain **key gaps and opportunities for exploring new strategies,** and **areas for innovation in practice** and **further research.**

The following areas are not exhaustive. We expect, and hope, that humanitarian organisations and actors, people with disability, and older people concerned with increasing inclusion in response will identify areas that we did not cover or that we missed. We also stop short of providing recommendations; we leave it to you to consider which areas fit best with your contexts, resources, and programming and research.



6.0 POTENTIAL AREAS FOR INNOVATION

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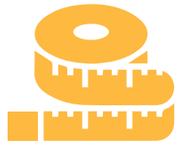
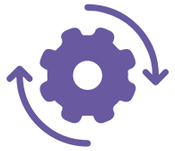


TAILORING TECHNICAL GUIDANCE AND TOOLS

2



DRIVING ORGANISATIONAL CHANGE

3

PUTTING MEANINGFUL PARTICIPATION INTO PRACTICE

4

UNDERSTANDING INTERSECTIONALITY

5

GOING BEYOND BASIC DATA COLLECTION

6

ALLOCATING RESOURCES AND MAINTAINING KNOWLEDGE

7

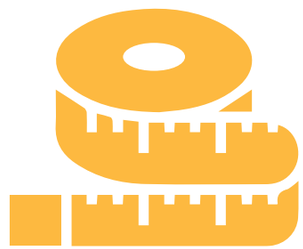
ADAPTING TO LOCAL AND DIVERSE CONTEXTS

6.1 TAILORING TECHNICAL GUIDANCE AND TOOLS

Recent literature, guidance and messaging on disability and older age inclusion have been advocacy-focused and there is now strong awareness of the need for disability and older age inclusion in the humanitarian sector. This has been formalised in global frameworks and commitments including the Sendai Framework and Charter on the Inclusion of People with Disability in Humanitarian Action. There is also awareness of related standards and guidelines among humanitarian professionals.

On the one hand, the lack of evidence on effective inclusive practice, and on the impacts of such practice, suggests that the need for advocacy is ongoing. On the other hand, there is the concern that **current messaging and guidance is not effectively providing humanitarian professionals with the tools and information they need to meet the specific needs of people with disability and older people in humanitarian settings.**

There is also a shortage of tailored technical and evidence-based guidance for specific sectors of work within humanitarian response. Where sector level guidance exists, such as for shelter, these do not always have sufficient detail or information appropriate for specific professional activities and contexts.

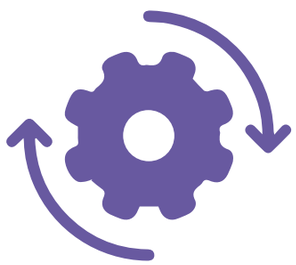


6.2 DRIVING ORGANISATIONAL CHANGE

A key issue that emerged from the Gap Analysis was the need to better **understand how organisational change and overcoming institutional barriers to meeting obligations and implementing guidance can result in more inclusive practice.** This appears all the more pressing as low awareness of the importance of the inclusion of people disability and older people no longer appears to be a major limiting factor.

The tendency for organisations to fall back on what they know and not to proactively break down silos they may work in is an obstacle to inclusion and falls short of meeting global commitments. This can mean **people with disability and older people are excluded from critical stages of response** and, particularly, in rapid onset emergencies. Unfortunately, it seems that inclusion remains an afterthought. **Increased awareness within the sector is not necessarily leading to prioritisation.** We also noted that attitudes to inclusion and humanitarian programming can remain biased towards a medical approach to disability.

Related gaps include limited published evidence, infrequent opportunities for exchange and networking among inclusion advisers and humanitarian 'generalists', and a need for more frequent identification and exchange of good practice. This applies to both disability and older age inclusion 'streams' and to professionals with related gender equality, diversity, and social inclusion roles. Better understanding and defining core competencies for inclusion advisors is an underexplored area. At the same time, **there is an urgent need to understand how change in organisations can be better driven and sustained from within.** There is also a clear need to improve understanding on how internal systems, mechanisms, attitudes and experience contribute to, or prevent, more inclusive humanitarian practice.



6.3 PUTTING MEANINGFUL PARTICIPATION INTO PRACTICE

All available guidance on disability and older age inclusion emphasises the need to engage with people with disability and older people directly. From the literature review, a large number of articles addressed access to humanitarian assistance and accessibility. However, **there was little evidence on the meaningful participation of people with disability and older people in response.**

This gap was mirrored in the interviews. Improving accessibility alone does not increase participation. Further, although there are signs that engagement and consultations with people with disability and older people are increasing in number, it is less clear that this is resulting in meaningful participation and positive outcomes. Despite some progress, **the voices and expertise of people with disability and older people remain marginalised.**

Moving beyond engagement, we need to address how to put meaningful participation into practice, how to build on successes, and how to support and develop good practices.

6.4 UNDERSTANDING INTERSECTIONALITY

There are clear linkages between disability and older age. There are also important differences, including fundamental issues of how people want to be identified and recognised. There may be points of tension and even discrimination between the two groups. Access to opportunities may also differ. While older people may lose opportunities they once had, some people with disability may never have had those opportunities at all. See 'Discussion Point' on page 31.

How people with disability and older people are represented may also differ. During the Gap Analysis we identified fewer OPAs than OPDs working in humanitarian response. In humanitarian settings, older people may not benefit from the collective voice that many people with disability have from being members of an OPD.

All these considerations have implications for inclusive response. **We need to better understand when and how, and under what circumstances it is beneficial (or not) to address disability and older age inclusion together** in humanitarian response. At the same time, **we need to know more about the intersectionality of age and disability with other identity characteristics,** such as gender, ethnicity, religion and sexuality and how experiences, specific needs and barriers to inclusion may change across the life course.

6.5 GOING BEYOND BASIC DATA COLLECTION

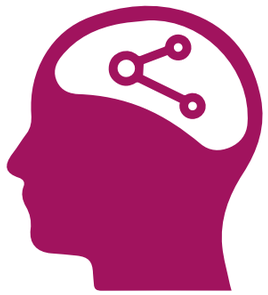
We found that the need for data disaggregated by disability and age was well understood. However, there is little evidence of this data being collected and used effectively in practice. The type of data that is increasingly being collected on disability in response is narrow. Data is usually collected on an individual's functional ability, using the Washington Group questions, rather than on barriers, access, or specific needs, such as health needs. Data on older people may not be disaggregated above 60 years of age. This renders the diversity of older age and related needs invisible.

Rapid assessments and analyses often do not provide the nuanced information needed to tailor responses to the specific needs of people with disability and older people. The time needed for tailored assessments can present challenges in the time-critical early stage of a response or when resources are scarce. Overall, there is a need to consider a **wider range of data collection tools and approaches** and how these can be implemented. The choice of tools should be based on the aims of data collection rather than simply on what tool is commonly used. Further, **the collection of data should not be seen as a proxy for inclusion.**

6.6 ALLOCATING RESOURCES AND MAINTAINING KNOWLEDGE

The need for allocating resources cuts across all the areas outlined above. While emphasised by some participants, it is not always clear that funding is the limiting factor for the inclusion of people with disability and older people in response. For example, it may be time rather than funding, particularly in complex and rapid onset emergencies. As noted above, this is when organisations may fall back on 'what they know best' rather than good practice. However, it was also clear **that we do not have clear evidence on the costs of inclusion in humanitarian response** overall or at different sector levels. This can impact on organisational change and be impacted on by a lack of available and appropriate data.

Human resources can also be a challenge. For example, staff turnover can lead to the loss of 'inclusion champions' within organisations, or external allies, and lead to challenges of maintaining knowledge resources. Organisations may also increasingly need technical inclusion experts with additional sectoral expertise to meet sector-specific needs. With demand for increasingly technical information on disability and older age inclusion, **strategies for accessing and sharing scarce technical expertise across and between responses may be required.**



6.7 ADAPTING TO LOCAL AND DIVERSE CONTEXTS

With the push towards 'localisation' there is a need to consider the universality of guidance, standards, and tools addressing the inclusion of people with disability and older people in humanitarian response. Importantly, how are approaches to inclusion being adopted and/or adapted? Are there mechanisms for local sharing of knowledge and how are these used and by who? Is peer-to-peer sharing of information between OPDs/OPAs and local response organisations more effective than with international responders?

Further questions to explore in this area relate to how we ensure the meaningful participation of people with disability and older people when there are no OPDs or OPAs in a given context. What are the particular challenges of ensuring inclusion in an area with no prior emergency or response compared to an area with frequent and repeat disasters? Currently, most guidance is general.

We have little evidence or guidance on ensuring inclusion in different and diverse humanitarian settings, and on what context-specific approaches may be best suited and most effective.

7.0

CONCLUDING REMARKS

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It is clear from the evidence presented that the inclusion of people with disability and older people is very much on the humanitarian agenda. Awareness is growing, standards and guidelines are recognised and, crucially, people with disability and older people are increasingly engaged in humanitarian response activities. **Progress has been made. This is encouraging, but there's still a long way to go.**

We do not yet have clear evidence of the effects of this relative progress. We know that data on disability and age is increasingly collected, but this data is rarely used to inform practice or to be responsive to barriers to inclusion. We know that growing awareness is not yet reflected in levels of institutional uptake of inclusive practice and organisational change. Despite some improvement, significant barriers to the meaningful participation of people with disability and older people persist in humanitarian response.

We hope our Gap Analysis can contribute to further progress on inclusion by informing innovation in this area and helping to prioritise areas for improved practice. We expect it to stimulate further efforts in research and assessments of progress, and hope to soon see more evidence of positive outcomes for people with disability and older people in humanitarian response. We call for the Gap Analysis to generate more reflection and discussion on what is really needed, by who, and where. That is essential if the humanitarian community is to deliver what works: practical, meaningful and sustainable solutions that ensure people with disability and older people are included, participate meaningfully, and have leadership roles in humanitarian response.

There is no shortage of gaps in evidence and practice. **But we look forward with positivity to sector-wide collaboration and collective action that rises to the challenge of filling them.**

FOOTNOTES

CLICK ON THE REFERENCE TO RETURN TO PAGE

A – 1.2
SUMMARY OF LITERATURE REVIEW FINDINGS

1) UN. 2015. Sendai Framework for Disaster Risk Reduction 2015-2030. United Nations, New York. https://www.unisdr.org/files/43291_sendaiframeworkfordrren.pdf

2) Charter on Inclusion of Persons with Disabilities in Humanitarian Response: Key principles to make humanitarian action inclusive of persons with disabilities, 2016. http://humanitariandisabilitycharter.org/

3) UN. 2006. Convention on the Rights of Persons with Disabilities. United Nations, New York. https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

4) Age and Disability Consortium. 2018. Humanitarian inclusion standards for older people and people with disabilities. https://reliefweb.int/report/world/humanitarian-inclusion-standards-older-people-and-people-disabilities

5) IASC. 2019. Guidelines: inclusion of persons with disabilities in humanitarian action. Inter-Agency Standing Committee. https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines

6) CHS Alliance. 2014. Core Humanitarian Standard on Quality and Accountability. https://corehumanitarianstandard.org/files/files/CHS%20in%20English%20-%20book%20for%20printing.pdf

7) Mirza M. 2011. Disability and humanitarianism in refugee camps: the case for a travelling supranational disability praxis, Third World Quarterly, 32:8. pp 1527-1536

8) Hunt M R, Chung R, Durocher E, & Henrys J H. 2015. Haitian and international responders' and decision-makers' perspectives regarding disability and the response to the 2010 Haiti earthquake, Global Health Action, 8:1

9) Berghs M. 2015. Radicalising 'disability' in conflict and post-conflict situations, Disability & Society, 30:5. pp 743-758

A – 2.1
DATA COLLECTION – INTERVIEWS

10) Ethics ID: 2056252

A – 2.4
PARTICIPANT SELECTION – INTERVIEWS

11) In this report, quotes from interview participants are used with the prefixes: 'OAI' for older age inclusion experts, 'DI' for disability inclusion experts and DPO representatives and 'M' for 'mainstream' actors. To reduce the possibility of participants being identifiable, we do not distinguish the particular type if there were fewer than three in the category.

B – 3.1
SETTING THE AGENDA

12) UN. 2015. Transforming our World: the 2030 Agenda for Sustainable Development. United Nations, New York. https://sustainabledevelopment.un.org/content/documents/21252030%20Agenda%20for%20Sustainable%20Development%20web.pdf

B – 3.2
TRANSLATING THE COMMITMENTS INTO PRACTICE

13) IFRC, Handicap International and CBM. 2015. All Under One Roof: Disability-inlcusive Shelter and settlements in Emergencies. International Federatio of the Red Cross and Red Crescent Socities, Geneva. https://www.ifrc.org/Global/Documents/Secretariat/Shelter/All-under-one-roof_EN.pdf

14) Refer to Annex to Part 1 of the Gap Analysis. https://www.elrha.org/wp-content/uploads/2020/07/ANNEX_Gap-Analysis_-inclusion-of-people-with-disability-and-older-people_Literature-Review2020.pdf

15) Ibid

B – 4.3
SHARING OF PRACTICE AND TECHNICAL ASSISTANCE

16) Palmer T et al. 2019. Inclusion of persons with disabilities in humanitarian action: 39 examples of field practices, and learnings from 20 countries, for all phases of humanitarian response. CBM, Humanity and Inclusion and the International Disability Alliance. https://interagencystandingcommittee.org/system/files/2019-12/Case%20studies%2C%20Inclusion%20of%20persons%20with%20disabilities%20in%20humanitarian%20action%2C%202019.pdf

B – 4.5
COLLECTING AND USING DATA

17) See the Washington Group on Disability Statistics for further information. http://www.washingtongroup-disability.com/

18) For examples, refer to Annex to Part 1 of the Gap Analysis. https://www.elrha.org/wp-content/uploads/2020/07/ANNEX_Gap-Analysis_-inclusion-of-people-with-disability-and-older-people_Literature-Review2020.pdf

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