

Light for the World  
**HOW-TO GUIDE**

# How to Build an Inclusive Data Ecosystem During Emergencies

A guide for humanitarian actors on reaching people with disabilities and older people: Practical tips from the Data That Matters project and the Survey for Inclusive Rapid Assessment (SIRA) tool



# Executive Summary

This Light for the World How-To Guide was created as part of the Data That Matters project. It serves as a **comprehensive guide for humanitarian actors** to building an inclusive data ecosystem to improve access for people with disabilities and older people to humanitarian services. It introduces the Survey for Inclusive Rapid Assessment (SIRA) tool, designed to identify the barriers and enablers these groups encounter when seeking humanitarian assistance. The guide emphasizes how **inclusive data practices can drive equity in humanitarian programming**.

The document begins by addressing the fundamental data problem: **people with disabilities and older people often remain invisible in humanitarian settings due to insufficient data collection practices**. Challenges such as stigma, inconsistent methodologies, and inaccessible tools contribute to this issue, ultimately hindering inclusive response efforts. In response, the guide outlines a **framework for creating an inclusive data ecosystem**, emphasizing inclusive identification and mapping, equitable data collection practices, and robust data sharing and analysis. These components are supported by strategies rooted in human-centred design, ethical data practices, and the application of the Washington Group Questions on Disability and the Child Functioning Module to ensure comprehensive disability identification.

The SIRA tool is a centrepiece of this guide. First of its kind, it is designed to be simple, flexible, and rapid. SIRA employs both quantitative and qualitative methods to **identify barriers and enablers to accessing humanitarian assistance**. Its adaptable structure allows for its application across diverse humanitarian contexts, ensuring it can generate actionable insights tailored to local needs. The tool's development involved extensive field testing and collaborative input from organizations such as OPDs, NGOs, as well as from affected communities, ensuring its relevance and inclusivity. The SIRA tool pursues **open-data and open-source principles** by making the digital data collection tool and code used for data analysis freely available online. The datasets generated from field testing are available in open formats and platforms.

In addition to its practical applications, the guide explores the broader implications of **inclusive data for advocacy** and humanitarian programming. It highlights how disaggregated data can inform advocacy efforts directed at governments, donors, and international organizations, enabling them to **address systemic barriers and enhance inclusivity in their policies and practices**. Furthermore, it demonstrates how this data can be used to design targeted interventions and inclusive mainstream programmes that remove barriers for marginalized populations while benefiting all affected individuals.

Ethical considerations are central to this framework. The guide underscores the **importance of non-extractive data collection practices** that offer tangible benefits to respondents, such as referrals to essential services. It also advocates for capacity development among persons with disabilities and older persons, empowering them to take active roles in data collection and analysis processes. Ultimately, this guide provides a roadmap for humanitarian actors seeking to design and implement disability- and older-age-inclusive interventions. By fostering the use of inclusive data, it aspires to **transform the humanitarian response landscape** into one that prioritizes accessibility, equity, and the meaningful participation of all individuals.

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## List of Abbreviations

|               |                                                                                                                                           |
|---------------|-------------------------------------------------------------------------------------------------------------------------------------------|
| <b>FAMOD</b>  | Mozambican Federation of Organizations of Persons with Disabilities<br>(Federação Moçambicana das Associações de Pessoas com Deficiência) |
| <b>HCD</b>    | Human-Centred Design                                                                                                                      |
| <b>HDX</b>    | Humanitarian Data Exchange                                                                                                                |
| <b>IASC</b>   | Inter-Agency Standing Committee                                                                                                           |
| <b>IDP</b>    | Internally Displaced Person                                                                                                               |
| <b>INGO</b>   | International Non-Governmental Organisation                                                                                               |
| <b>IOM</b>    | International Organization for Migration                                                                                                  |
| <b>NNGO</b>   | National Non-Governmental Organisation                                                                                                    |
| <b>OPD</b>    | Organisation of Persons with Disabilities                                                                                                 |
| <b>OPA</b>    | Older Persons Association                                                                                                                 |
| <b>SIRA</b>   | Survey for Inclusive Rapid Assessment                                                                                                     |
| <b>UN</b>     | United Nations                                                                                                                            |
| <b>UNCRPD</b> | United Nations Convention on the Rights of Persons with Disabilities                                                                      |
| <b>UNHCR</b>  | United Nations High Commissioner for Refugees                                                                                             |
| <b>UNICEF</b> | United Nations International Children's Fund                                                                                              |
| <b>UNOCHA</b> | United Nations Office for the Coordination of Humanitarian Affairs                                                                        |
| <b>WASH</b>   | Water, Sanitation and Hygiene                                                                                                             |
| <b>WGQ</b>    | Washington Group Questions                                                                                                                |
| <b>WG-SS</b>  | Washington Group Questions – Short Set                                                                                                    |
| <b>WG-ES</b>  | Washington Group Questions – Extended Set                                                                                                 |





# 1

## Introduction

# How to Use this Guide

This How-to Guide shares learnings and provides step-by-step guidance on building an inclusive data ecosystem that can support humanitarian actors in better reaching persons with disabilities and older persons. Four chapters guide the reader across the main topics in disability- and older-age inclusive data for humanitarian action:

- **Chapter 1 outlines the data problem.**  
Why are the needs of persons with disabilities and older persons in emergency settings not known? What are the key aspects of the data problem? What role can different actors play?
- **Chapter 2 discusses the three main components of an inclusive data ecosystem.**  
For each component, the strategies put in place as part of the Data that Matters project are discussed, together with learnings from project implementation, and ensuing recommendations. This section highlights the findings arising from the conceptualisation, design, development and testing of the SIRA tool during the project.
- **Chapter 3 presents the Survey for Inclusive Rapid Assessment (SIRA) tool.**  
What is SIRA? How can it be used to assess the barriers and enablers persons with disabilities and older persons face in accessing humanitarian assistance? How does SIRA support open-data and open-source initiatives?
- **Chapter 4 provides guidance on using inclusive data to support inclusive humanitarian action.**  
Once data and tools are available, how can a more inclusive data ecosystem support evidence-based decision-making? How does the data – e.g. from SIRA – serve advocacy efforts and/or humanitarian programming? How can we ensure the data cycle is not only extractive in nature and offers a direct benefit to those that provide information? In other words, how can disability- and older-age-inclusive data be used for referrals, the provision of inclusive humanitarian assistance, and/or advocacy efforts?

### How to read this guide:

- ◆ For humanitarian actors interested in a disability and/or older age **mainstreaming approach**, chapters 1, 2 (sections 1), 3, and 4 (sections 2 and 3) are most relevant.
- ◆ Humanitarian actors seeking to implement **targeted interventions** will find the most relevant information in chapters 2, 3, and 4 (sections 1 and 3).
- ◆ Organisations with a focus on **advocacy** for disability- and older-age inclusion in humanitarian settings will gain most benefit by reading through chapters 2 and 4, with other sections of the step-by-step guide being also relevant.



# Background

In humanitarian contexts, people with disabilities and older persons often become invisible due to a lack of accurate data. For instance, in Cabo Delgado, Mozambique, the total number of people with disabilities is unknown. This is because of frequent population movements and inconsistent data collection methods among humanitarian actors, who use different tools to determine vulnerability.<sup>1</sup> There is also limited evidence on the identification of older people in humanitarian responses, largely because data on them is not routinely collected<sup>2 3 4</sup>, making them invisible in humanitarian settings.<sup>5</sup>

The aim is to improve access of persons with disabilities and older persons to humanitarian assistance by informing humanitarian programming, supporting advocacy efforts and facilitating effective referrals for persons identified with specific vulnerabilities.

This guide draws on the research conducted by Light for the World, FAMOD<sup>i</sup> and Design Innovation Group in Mozambique in 2023 and 2024, developing and testing the Survey for Inclusive Rapid Assessment (SIRA) tool.



# The Data Problem



The challenges faced by humanitarian programmes in including persons with disabilities and older persons in emergency and crisis contexts stem from the difficulty in obtaining reliable data.

Identifying the target group within the community and disaggregating data pose significant obstacles. Inclusive data collection must also address cultural barriers such as discrimination and stigma, as many individuals with disabilities do not openly discuss the barriers they face.



# The Data Problem



The data problem entails multiple dimensions which reinforce themselves, hence the need to target multiple aspects as part of an inclusive ecosystem approach. These aspects can be grouped in three broad categories:

- Data collection tools and methods are inadequate.
- Persons with disabilities are not involved in the data collection process and subsequent data usage.
- Data and tools are not disseminated and taken up.

Although it may not be feasible for a single actor to target all aspects at once in a single intervention, given the importance of achieving better disability and older-age inclusion, it is important to keep a comprehensive view of the problem and design multi-faceted data strategies in response.

# What Defines an Inclusive Data Ecosystem

The guiding principle of inclusive humanitarian action is to ensure that no one is left behind. Achieving this goal requires addressing the barriers faced by individuals with varying degrees of vulnerability.

**An inclusive data ecosystem means that the collection, management, analysis, and sharing of data are all conducted in an inclusive and accessible manner.** In the context of humanitarian action, such inclusive data must inform programming and support advocacy efforts.

Ultimately, an inclusive data ecosystem aims to ensure that the perspectives of all crisis-affected people are considered and acted upon. By doing so, it provides a first step toward ensuring equal access to humanitarian services. The subsequent step is the willingness and know-how to use this data to create an inclusive humanitarian response.

Reaching the hardest-to-reach populations requires the meaningful participation of affected populations in the humanitarian response. Involving representative organizations – such as Organizations of Persons with Disabilities (OPDs), Older Persons Associations (OPAs), women's organizations, and youth organizations – can facilitate this process when they are present. International Non-Governmental Organizations (INGOs) can provide technical support and expertise on data and humanitarian programming to assist representative organizations as part of localisation efforts.







## 2

# **Building Disability and Older-age Inclusive Data Ecosystems for Humanitarian Action**



# Fostering an Inclusive Data Ecosystem

The content of this chapter stems from the experience of the Data That Matters project and the implementation of the SIRA rapid assessment tool in Cabo Delgado, Mozambique in 2024.

The chapter outlines three target areas for developing an inclusive data ecosystem:

- i) identifying and mapping target groups,
- ii) inclusive data collection,
- iii) and analysing and disseminating data to support more inclusive humanitarian action.

These three aspects respond to the categories underpinning the data problem (see chapter 1, pp. 5-10)

Inclusive identification and mapping focuses on the ethical and effective characterisation of the target population group, in particular persons with disabilities. Key questions include: what is the prevalence of disability? Who are the persons with disabilities? How can we better identify persons with invisible disabilities?

Disability- and older-age-inclusive practices for sampling and data collection aim at ensuring meaningful participation of these two target groups in the data collection process. It also aims at capacity strengthening of all humanitarian actors, and the use of accessible technologies and formats for both enumerators and respondents.

Data analysis and dissemination centres on the effectiveness and sharing of:

- i) relevant tools and methods for the analysis of disaggregated data, and
- ii) inclusive data and findings to support evidence-based decision-making.

The content of the chapter is drawn from the Data that Matters project, namely: what it aimed to achieve in terms of inclusive data strategy, what the successes and failures (learnings) were, and recommendations that could be drawn from it.

Three areas for inclusive an inclusive data ecosystem:



**Inclusive identification and mapping**



**Inclusive practices for sampling and data collection**



**Data analysis & dissemination**

# Inclusive Identification and Mapping

## Background

Identification of target groups is a first step in reaching them. When it comes to disability, there are several key issues around inclusive identification:

1. The model of disability, and understanding by stakeholders on what is a disability;
2. Stigma and access to persons with disabilities;
3. Self-identification versus community-based identification versus census-based tools such as the Washington Group Questions;
4. Ethics of identification when gaps in intervention reach are to be foreseen.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) builds on a social model of disability whereby disability is the product of an impairment in interaction with existing barriers. The impairment may be sensory (visual, hearing), linked to mobility, intellectual, psychosocial or multiple; whereas barriers may be environmental, attitudinal, institutional or around communication. By establishing an international legal framework, the UNCRPD further binds the social model of disability into a human-rights based model.

Stigma drives exclusion, and some types of disabilities are more stigmatized than others at community level. This stigma entails a social cost of disability, leading to individuals, family or community efforts to make disability invisible. Compounded by intersectionality, some individuals may become hard to identify and subsequently to reach.

Self-identification is easily prone to error – with persons mistakenly identifying as having or not a disability – either due to response bias or stigma and lack of awareness. Community-based identification – e.g. through key informants or community leaders – is a rapid and more effective approach but may also be exclusionary of specific individuals and/or disability types.

The Washington Group (WG) set of questions is currently the best tool for identifying persons with disabilities based on the social model of disability. However, the WG's principal purpose is to assess disability prevalence in a population and not identifying specific individuals in the scope of programme delivery.<sup>7</sup> Depending on the set of questions used – short (WG-SS) vs extended set (WG-ES) – important impairments may be excluded, e.g. anxiety and depression. Disability prevalence estimates require a random sample, large number of observations, technical expertise and logistical as well as financial capacity. Moreover, the prevalence estimate will depend on the set (and functional domains) being used.<sup>8</sup>

Identification always comes with some risk, with direct ethical and operational implications in a humanitarian context. The best strategy for inclusive identification is context-dependent. However key principles can guide our approach.



# Inclusive Identification and Mapping

### Guiding questions:

The following questions directly link to the content of this section.

- ◆ How is disability identified and by whom?
- ◆ What is the prevalence of disability in the target area?
- ◆ What are the key ethical issues associated with identification of persons with disabilities and how does this relate to the do-no-harm principle?
- ◆ How do different vulnerabilities – such as displacement status and intersectionality – affect identification?
- ◆ Does programme design and implementation affect which approach can be taken to identification?



# Inclusive Identification and Mapping

## Strategies

Below are the key strategies applied by the Data That Matters project to ensure inclusive identification and mapping:

### Identification through Washington Group Questions

The humanitarian sector may still approach disability through a medical model that is now outdated for this purpose.<sup>7</sup> By making use of the Washington Group questions, the project grounded identification of persons with disabilities in the human rights-based model. In addition to a prevalence of disability estimate, the Washington Group questions could guide the interpretation of the barriers and enablers for persons with disabilities and older persons in accessing humanitarian assistance.

### Combining the short and extended Washington Group sets

The short set (WG-SS) provides an internationally accepted and comparable identification of key disability types (mobility, visual, hearing, intellectual). To enable the identification of frequently invisible and therefore potentially underserved disabilities, the development of the survey tool also borrowed specific functional domains from the extended set (WG-ES): anxiety, depression, fatigue and pain. The latter two functional domains were included with a specific focus on older persons.<sup>9 10</sup>

### Random sampling and large sample size

The project aimed for random sampling to ensure disability prevalence could be estimated. Large numbers increase the probability of covering specific groups within the population and of extracting reasonable information about these from the data. Sample size was calculated with the interaction of sex, age, disability and displacement status in mind.

### Ethics of identification and benefits of referrals

Delivery of humanitarian assistance was not part of the project nor a direct follow-up from it. Consequently, identification was not directly linked with access. By design, identification would be associated with the risk of identifying persons that would then not be supported due to gaps in delivery. The project also aimed to provide referrals at the time of data collection/identification. As a process, this can ensure immediate benefits are made available to identified individuals.

# Inclusive Identification and Mapping

## Learnings

Below are key learnings from the Data That Matters project regarding inclusive identification and mapping:

### Identification through Washington Group Questions

**Partial Success:** Low prevalence of certain functional impairments – namely hearing and mobility – pointed to difficulties in identification. After Action Reviews revealed this was partly due to the existence of household-/family-level barriers during survey. Field research in survey areas also indicated lack of formal sign language knowledge and usage, with hearing impaired persons relying on informal signing. This points to a lack of reasonable accommodation in the form of an appropriate local interpreter and in general to the difficulty in ensuring persons with certain impairments are not being excluded.

### Combining the short and extended WG sets

Certain functional domains weighted more heavily in the final disability prevalence. For example, cognitive, anxiety, and depression showed high prevalence, while hearing and mobility were less well captured. The issue might be linked to sampling and access to individuals.

**Success:** Including Washington Group questions covering psychosocial functional domains – anxiety, depression and fatigue – resulted in a much larger disability prevalence estimate. This was especially the case for older persons, who also exhibited a high prevalence of functional impairment for pain and fatigue. Borrowing functional domains from the WG-ES had a clear impact on identification.

### Random sampling and large sample size

**Success:** A large sample size was necessary to ensure adequate coverage of sex, age, disability and displacement status – providing some intersectional data.<sup>11</sup> Sample size quickly becomes prohibitive in aiming to cover more ground.

**Failure:** Despite a two-stage stratified clustered sampling,<sup>12</sup> household- and family-level barriers – not linked to gender – prevented the correct implementation of the Washington Group questions thus affecting disability prevalence estimates.

Depending on the setting, it might be simpler to rely on community-based identification in conjunction with targeted focus group discussions on barriers and enablers. Representative organisations or field workers may facilitate this process. If working with a pre-identified group, the ethical and cost-benefit value of using the Washington Group questions in addition is open to debate.<sup>13</sup>

### Ethics of identification and benefits of referrals

The project was not confronted with the ethical dilemma of potentially identifying more target individuals than what could be reached by the programme – a very real concern in other settings.

**Success:** By providing service referrals to respondents, the project ensured they could benefit from their participation, offering a meaningful strategy to keep data collection ethical.



# Inclusive Identification and Mapping

## Recommendations

### Identification through Washington Group Questions

Be aware of issue that all disability types may not be correctly sampled. Digital data collection tools allow for real time monitoring which may in turn allow for corrective action to be taken. Complement survey-based methods centred on WG with focus group discussions involving persons with different types of disabilities. These may be community-identified individuals – e.g. through representative organisations and/or field workers.

### Combining the short and extended WG sets

Include questions that cover the psychosocial and pain functional domains, as these are crucial for:

- detecting a large and otherwise invisible part of the population with psychosocial disability,
- the inclusion of older persons with disabilities, who are disproportionately affected by pain and psychosocial impairment.<sup>10</sup>

Results from using both the short (WG-SS) and extended sets (WG-ES) of Washington Group questions can directly inform programming and advocacy. The operational and programmatic value of the data provided by WG should be prioritized over strict adherence to the six-question short set (WG-SS) that was primarily designed to provide internationally comparable disability prevalence data in non-emergency settings.<sup>8 14</sup>

### Random sampling and large sample size

Make use of a sound sampling strategy and aim for the largest sample size possible. If disability prevalence is not a key focus, assumptions over randomness can be relaxed thanks to computational techniques that can be implemented during analysis, such as permutation-based methods like Fisher's Exact Test.

### Ethics of identification and benefits of referrals

Carry out referrals during data collection as it provides support to respondents hence supporting a more ethical data collection process.

# Inclusive Identification and Mapping

## Stakeholders

### Stakeholder Mapping: Users and Providers of Data

The diagram highlights the diverse stakeholders engaged in the humanitarian ecosystem, as identified by the Data That Matters project. These stakeholders represent a wide array of actors, including communities, civil society, governments, international organizations, and academia. Each plays a dual role, both providing and utilizing data, in advancing the inclusive identification and mapping of persons with disabilities.



# Disability and Older-age Inclusive Practices for Data Collection

## Background

Data collection practices that are inclusive of persons with disability and older persons can centre on either or both enumerators and respondents. Approaches build on meaningful and effective participation, and accessibility.

### **Inclusive practices for enumerators:**

By leading or being involved in data collection, persons with disabilities and older persons gain in visibility and leadership, breaking the cycle of invisibility in the data collection process.<sup>6</sup>

When persons with disabilities and older persons serve as survey enumerators, they encourage the participation of other persons with disabilities and older persons by acting as role models, which helps reduce stigma around disability. This role modelling challenges the capability paradigm, which often assumes that persons with disabilities and older persons are expected to achieve less.<sup>15</sup>

When enumerators come from the surveyed communities, their involvement empowers affected populations to participate actively in data generation. Including representative organizations, such as Organizations of Persons with Disabilities (OPDs) and Older Persons Associations (OPAs), also supports localization efforts within the crisis response.<sup>16</sup>

To ensure that persons with disabilities can conduct surveys on an equal footing with others, the formats and tools used must be accessible. This includes using simple and context-appropriate language in questionnaires instead of highly technical terms, providing reasonable accommodation such as sign language interpreters, and ensuring digital data collection tools are screen-reader compatible.

### **Inclusive practices for respondents:**

Effective and meaningful participation of respondents can:

- ensure people in all their diversity are represented in the data, and
- mitigate the extractive nature of the data collection process

Balanced representation requires that both identification (see chapter 3 pp. 32-43) and data collection are inclusive – with data collection instruments and protocols, carefully designed to account for diverse accessibility needs.



### Disability and Older-age Inclusive Practices for Data Collection

In the case of persons with disabilities and older persons, individuals may have hearing, seeing, mobility, cognitive, psychosocial, other types of impairments, or a combination of these. Even when formal exclusion criteria are removed, persons with disabilities and older persons can be underrepresented if the methods and logistics of data collection do not provide reasonable accommodation.

Leading or participating in data collection can empower persons with disabilities and older persons and encourage a better understanding of the specific requirements respondents with disabilities and older respondents have. In addition, such involvement can reduce the intrusiveness of data collection. For example, questions on mental health have been reported as being sensitive in given contexts due to stigma.<sup>17</sup> Balancing information flow can also help mitigate the extractive nature of data collection - for example, through referrals (see chapter 4, pp. 44-53).

#### Guiding questions:

**The following questions directly link to the content of this section.**

- ◆ How can data collection be more inclusive of enumerators and respondents with disabilities and or older enumerators/respondents?
- ◆ What role can enumerators with disabilities play in promoting disability inclusion at community-level?
- ◆ What measures can be taken to mitigate the extractive nature of data collection?
- ◆ How do inclusive data collection practices promote the participation of affected populations and the localisation agenda?

# Disability and Older-Age-Inclusive Practices for Data Collection

## Strategies

Disability- and older age-inclusive data collection aims for meaningful and effective participation of enumerators and respondents alike. A few strategies for inclusive data collection were tested in the Data that Matters project:

### Persons with disabilities as role models

The data collection was coordinated by an organisation of persons with disabilities (OPD), with persons with disabilities and older persons in the lead. Besides promoting meaningful and effective participation of OPD members, the approach was aimed at empowering persons with disabilities and older persons as enumerators. Moreover, we expected interviewees who also face functional barriers to feel more comfortable and represented when interacting with enumerators who may share similar experiences. This connection in turn led to a more positive and open exchange during data collection.

### Organisation of people with disabilities and the inclusion lens

Disability awareness should be addressed from the very beginning of a data collection programme, such as during training sessions for enumerators and facilitators. This can be achieved by sensitizing enumerators through role-play activities, where they encounter challenging scenarios involving accessibility and communication barriers. Through these exercises, they can experience potential obstacles firsthand and collaboratively strategize solutions. It's also important to recognize the diversity of disability types, ensuring that enumerators understand the distinct needs associated with each – i.e. in view of providing reasonable accommodation. Additionally, older persons should not be automatically assumed to be community elders or leaders, as this distinction varies across individuals and contexts.

### Inclusive and accessible communication

Language barriers, translation issues, low literacy rates, and hearing and speech impairments are significant challenges to effective communication during data collection. It is essential to work closely with enumerators, as they will be translating questions into local languages, providing context, and using sign language or picture books when necessary. Reviewing the questionnaire with enumerators ensures they fully understand the questions and creates an opportunity for them to suggest improvements that simplify and contextualize the language used.

### Referrals of respondents

Providing referrals helps balance the extractive nature of data collection by offering tangible benefits to survey respondents. In a humanitarian response setting, assisting individuals in need is an obligation. When an organization or individual cannot provide direct help, referring people to other organizations can fulfil this responsibility. Data collection offers a valuable opportunity to provide these referrals, ensuring respondents benefit from their participation.

# Disability and Older-age Inclusive Practices for Data Collection

## Learnings

Below are key learnings from the Data That Matters project in the area of Disability- and Older-Age-Inclusive Practices for Data Collection:

### Persons with disabilities as role models

**Success:** During After Action Reviews, persons with disabilities that participated as enumerators in data collection reported feeling empowered by the skills learnt and experience gained.

**Success:** Older enumerators and enumerators with disabilities also reported perceiving a positive shift in the community's perception of persons with disabilities and what they can achieve.

### Organisation of people with disabilities and the inclusion lens

**Success:** OPD members are experts on inclusion. Leading the data collection process helped ensuring that disability was not approached from a medical perspective.

**Failure:** Although all enumerators were OPD members, half of them were persons with disabilities and the team included older persons, there was a tendency to emphasize the survey's mainstream dimensions rather than the disability and older age inclusion aspects. Even when field coordinators and key enumerators were involved in survey testing, there was no automatic inclusion lens applied by persons with disabilities, older persons, or representative organizations. This highlights the need for specific, practical training on the connection between sections of the questionnaire and disability or older-age inclusion regardless of enumerator background.

### Inclusive and accessible communication

**Failure:** Using picture books for survey purposes proved challenging, particularly with older persons.

**Success:** Simple language facilitated easier translation into the local language, Makhuwa, improving communication overall.

A significant barrier highlighted by older respondents and those with disabilities was the lack of accessible communication options in the current humanitarian context.

**Success:** Digital data collection tools with screen reader compatibility ensured enumerators with visual impairments could effectively run the questionnaire.

**Partial Success:** Although reasonable accommodations, such as providing a sign language interpreter, allowed enumerators with hearing or speech impairments to participate in data collection, some respondents with similar impairments did not speak sign language, limiting their full participation.

### Referrals of respondents

**Success:** 60% respondents received a referral. This was seen as beneficial by respondent who widely shared the perception that communication is often not sufficiently accessible in the surveyed areas. Referrals focused on WASH and health services.



# Disability and Older-age Inclusive Practices for Data Collection

## Recommendations

### Persons with disabilities as role models

Participating in or leading data collection can be an empowering experience, helping to positively shape community perceptions of disability and older age. International NGOs can play a key role through technical support to OPDs and OPAs, offering expertise and facilitating co-creation and adaptation of tools for data collection. After Action Reviews and participatory methods can be used after data collection to capture and build on insights and learnings from the process.

### Organisation of people with disabilities and the inclusion lens

Organizations of Persons with Disabilities (OPDs) may not be present in all emergency settings. However, it is still essential to involve persons with disabilities in data collection. Targeted training on the connection between specific questions in the data collection tool and the inclusion of persons with disabilities and older individuals is key even when enumerators are inclusion experts. Role-play and mock interview exercises can be highly effective for this purpose.

### Inclusive and accessible communication

Using simple language is an effective way to support participation. Alternative communication formats, such as picture books, require significant investment for development and testing to determine the best layout. Providing reasonable accommodation is essential for both enumerators and respondents, though it can be more challenging to achieve for respondents. Careful planning and consideration are needed to ensure the best possible inclusion outcomes. Conducting small-scale field research beforehand can help identify promising strategies for effective reasonable accommodation – e.g. for persons with functional impairments related to hearing and/or mobility domains.

### Referrals of respondents

Use the survey as an opportunity for providing referrals, which helps balance the otherwise extractive nature of data collection. Consider integrating referrals into feedback mechanisms when appropriate.<sup>18</sup>

# Disability and older-age Inclusive Practices for Data Collection

## Stakeholders

### Stakeholder Mapping: Users and Providers of Data

The diagram showcases the range of stakeholders involved in the humanitarian ecosystem, as recognized by the Data That Matters project. Spanning communities, civil society, governments, international organizations, and academia, these actors are integral as both contributors and users of data. Their efforts focus on implementing disability- and older age-inclusive approaches to sampling and data collection, ensuring these groups' meaningful participation throughout the process.



# Data Sharing and Analysis

## Background

Data is central to understanding the needs of affected populations, the operational context and the humanitarian response. Data plays a critical role across the entire programme cycle and further supports advocacy and research efforts.

### Data Sharing

Besides generating new data, existing data also needs to be effectively shared among humanitarian actors. Indeed, when looking at the ‘data problem’ for disability and older age inclusion in humanitarian action, a central issue is data sharing (see chapter 1, pp. 5-10).

In recent years, open data practices have been developed for collecting, sharing, and utilizing data that is freely available and accessible to anyone involved in or impacted by humanitarian work. Crucially, open data is typically provided in open formats that allow for easy access, analysis, and use, with the added goal of improving transparency and timeliness, enhancing coordination among humanitarian actors, and inform decision-making for more effective responses to crises. As such, open data may offer a framework for addressing the data gaps for disability and older age inclusion.

UN-OCHA’s Humanitarian Data Exchange (HDX) currently provides a centralized hub for open data, enabling humanitarian actors to share, access, and analyse data from multiple sources. At the time of writing (November 2024), HDX hosted over 800 datasets with disability-specific data and approximately 200 datasets with older-age specific data.

### Data Analysis

To feed into humanitarian programming and advocacy or research initiatives, data must be turned into actionable evidence. Ensuring common standards for analysis can improve comparability and sharing of findings among actors, providing a common understanding of humanitarian needs and context.

Similarly to open data, open source for humanitarian action involves using and creating software, tools, and resources with publicly accessible code that anyone can use, modify, and distribute freely. This approach enhances collaboration, transparency, and innovation in the humanitarian sector, allowing for faster, cost-effective, locally-adapted and scalable solutions to meet urgent needs.

Facilitating analysis of disability- and older age-relevant data can support efforts to establish best practices and derive meaningful, actionable data for humanitarian action.



# Data Sharing and Analysis

### Guiding questions:

The following questions directly link to the content of this section.

- ◆ How can disability- and older age-relevant data be effectively shared among humanitarian actors? What are the benefits?
- ◆ Which solutions can be put in place to facilitate rigorous analysis of disability- and older age-relevant data in humanitarian settings?
- ◆ How can the analysis itself be made more inclusive of persons with disabilities and older persons?



# Data Sharing and Analysis

## Strategies

Older age and disability data relevant to humanitarian settings should be effectively shared among relevant actors to support an adapted and coordinated response. Similarly, common tools and methodologies for analysis should be implemented to ensure comparability of findings and coordination of response in line with best available practices for disability and older age inclusion. Importantly, to be relevant to affected populations, data and analyses require accessible language, learning and reflection, and active community participation.

Below are a number of strategies employed by the Data That Matters project:

### Open data

The project aimed to make all data generated available on UN-OCHA's HDX, offering computationally efficient datasets in open formats while implementing necessary data safeguarding measures before release. In addition to sharing datasets, the project proceeded with publishing of a freely accessible interactive dashboard<sup>i</sup> to allow users to explore some of the data and results from SIRA implementation.<sup>ii</sup>

### Analysis of disability and older age disaggregated data

Analyses should extend beyond health to explore additional dimensions of disability and older age in humanitarian settings. By including both qualitative and quantitative data the project aimed to also capture the lived experience of disability and older age in relation to humanitarian access. All analyses included disaggregation by disability and older age, with further breakdowns by sex and displacement status to investigate intersectionality.

### Open source

The data collection tool and computer code used for developing data analysis tools should be made freely available online. This includes the code used to develop the interactive web application/dashboard developed for analysis of SIRA results.<sup>ii</sup> Besides promoting adaptation and adoption of tools, this approach aims to facilitate collaborative code development and improvement of the analysis web application/dashboard. All analyses should be based on free and open-source tools such as R, Python and open-source artificial intelligence (AI) models.

### Emergent learning

The project aimed to capture key learnings around the inclusivity of identification and data collection with enumerators and additional OPD members. The project also aimed to analyse and interpret results and findings with OPD members, especially on barriers and enablers persons with disabilities and older persons face in accessing humanitarian assistance.

# Data Sharing and Analysis

## Learnings

Below are key learnings from the Data That Matters project.

### Open Data

**Success:** Key informant interviews and focus group discussions with humanitarian actors in Mozambique highlighted demand for a centralised database or repository for sharing disability- and older-age-relevant data. In this project, data could rapidly and effectively be shared via UN-OCHA's Humanitarian Data Exchange (HDX) platform.

**Partial Success:** However, disability and age disaggregation contributed to non-negligible risk under statistical disclosure control.<sup>iii</sup> This affected both the process for sharing data, the underlying data formatting, and most importantly the type of data disaggregation that could be made available, reducing the usefulness of the published data to other organizations. This was addressed by providing data on request via HDX connect.

**Success:** Results were effectively shared via an interactive online app – providing access to key elements of the data, while ensuring privacy safeguarding and the capacity to explore results without needing advanced data analysis know-how.

### Analysis of disability and older age disaggregated data

**Success:** The Washington Group questions (WG), selected from both the short (WG-SS) and extended (WG-ES) sets, were effectively used to disaggregate data across all or specific functional domains selected. An overall disability prevalence was calculated and compared with results obtained by including or excluding specific functional domains - for example, to assess the impact of psychosocial domains on disability prevalence in IDP camps.

**Success:** Qualitative data complemented the information from the WG and age and sex disaggregation, offering insights into the processes behind observed differences.

**Failure:** Unfortunately, the project did not have the opportunity to provide feedback and discuss results with affected communities beyond representative organisations before its planned end.

### Open source

**Success:** All relevant code developed in the project was successfully shared online, free of charge, on GitHub.<sup>iv</sup>

**Success:** The web application developed for interactive visualisation of disability- and age-disaggregated results was easily accessible for users from PC or smartphone.

**Partial Success:** Ensuring interactivity of the dashboard constrained the types of analyses and visualizations that can be displayed. Indeed, maintaining the coherence of the displayed data, making sure information is easily digestible without expert knowledge, and ensuring rendering, all posed significant design constraints. Additional formats and layouts could have potentially facilitated interpretation and use of results for disability- and older-age inclusion even more.



# Data Sharing and Analysis

### Emergent learning

**Success:** After-action reviews and sense-making workshops provided all enumerators with an opportunity to share their personal experience of the survey and which outcomes they expected from their participation. Enumerators with disabilities and older enumerators shared insights on the feeling of empowerment coming from participating in data collection exercise, and the positive image for persons with disabilities and older persons projected at community level. Overall, the workshops highlighted strengths and shortcomings of the data collection tool and process in terms of effectiveness and inclusion.

## Recommendations

### Open data

Sharing data on UNOCHA's Humanitarian Data Exchange (HDX) is an effective approach to making valuable information available to other humanitarian organisations. When using SIRA or sharing individual or household survey data more broadly, relevant statistical disclosure techniques need to be applied beforehand to ensure respondents privacy and safeguarding. HDX conducts such analysis when users flag the data as potentially sensitive during upload.<sup>19</sup> Inevitably, sharing data carries safeguarding risks that must be carefully mitigated.

### Analysis of disability and older age disaggregated data

Analysis should build on the available disaggregation of data by disability and older age, alongside sex and other relevant population characteristics, such as displacement status. Investigating intersectionality of data is critically important. Making use of mixed methods leverages the relative strengths of both quantitative and qualitative methods - highlighting both the commonalities and specificities among and between groups, while also providing valuable insights into the potential processes that explain any of the observed differences.

### Open source

Participating in the development and sharing of open-source tools to support transparency efforts with regards to analyses and generation of findings for evidence-based decision-making in humanitarian setting. In so-doing support alignment between actors and facilitate third-party access to cost-effective technical solutions. International NGOs can play a unique technical support role in helping smaller, local organizations to adapt and utilize state-of-the-art open-source tools. Make use of available open source tools - for instance for statistical disclosure control.<sup>20</sup> The open source ecosystem enables users to access advanced technology and methodologies for free and aided by substantial documentation.

# Data Sharing and Analysis

### Emergent learning

Ensuring after-action reviews and sense-making workshops are part of the survey cycle to provide a means of capturing emergent learning on inclusive practices. Co-creation methods can empower persons with disabilities, older persons, and their representative organizations to define their own data analysis and learning objectives (see chapter 2, pp. 11-31).



# Data Sharing and Analysis

## Stakeholders

### Stakeholder Mapping: Users and Providers of Data

The diagram outlines the key stakeholders in the humanitarian ecosystem, as identified by the Data That Matters project. These stakeholders encompass a broad spectrum, comprising communities, civil society, governments, international organizations, and academia, who play both user and provider roles. Their involvement supports the analysis and dissemination of data that reflects the experiences and needs of persons with disabilities and older persons.







# 3

## **SIRA: Survey for Inclusive Rapid Assessment of Barriers and Enablers in Accessing Humanitarian Assistance**

## The Survey for Inclusive Rapid Assessment (SIRA) Tool

The Survey for Inclusive Rapid Assessment (SIRA) aims to identify the barriers and enablers that persons with disabilities and older persons face in accessing humanitarian assistance. The tool is:

- **Simple** – to ensure accessible and straight-forward data collection in complex settings
- **Flexible** – to adapt to diverse needs and context, while maintaining alignment and a common infrastructure
- **Informative** – provides key information on priority areas for more inclusive humanitarian action
- **Rapid** – digital format and open data principles ensure turn-around time from data to evidence is strongly reduced

This mixed-methods tool leverages quantitative and qualitative data to identify patterns and investigate lived experiences and/or the non-linearity of processes occurring on the ground.

Open-data and open-source principles are used to ensure tools can be adapted and adopted by other actors – including for data collection and analysis – and data and key findings are made available to the humanitarian and academic communities in a common format.

Design principles were defined from the bottom-up in a collaborative fashion:

- Human-centred design with humanitarian actors, OPDs, NGOs and field workers
- Field research in IDP camps of Cabo Delgado, Mozambique, and desk research into current state-of-the art from academia and practitioners
- Collaborative development of a Theory of Change involving humanitarian actors, OPDs, NGOs and academia
- Extensive cognitive and field testing

SIRA can be used in diverse humanitarian settings and is suitable throughout the emergency response cycle – albeit less so at emergency onset, when situational constraints may limit access to key information and training. At emergency onset, mapping and providing referrals (see chapter 4, pp. 44-53) and adapting the Washington Group Questions to local language (next page) might not be feasible.

## Adapting the Washington Group Questions

The Washington Group Questions are standardized tools designed to identify individuals with disabilities by assessing functional impairments in key areas, known as functional domains. Instead of diagnosing medical conditions, these questions adopt the social model of disability as outlined in the United Nations Convention on the Rights of Persons with Disabilities.<sup>21</sup> This approach is based on the World Health Organization's International Classification of Functioning, Disability, and Health.<sup>22</sup>

The Washington Group Questions (WGQ) have proven effective in generating internationally comparable data on disability prevalence, providing accurate estimates of the number of persons with disabilities in affected populations. This improves needs assessments and resource mobilisation.<sup>23</sup> The questions are valuable for estimating disability prevalence in target areas and for linking functional impairments to specific barriers and enablers people face in accessing humanitarian assistance.

Key learnings from the implementation of the Washington Group questions in the Data that Matters project include:

- The importance of including mental health functional domains from the extended set of Washington Group questions.
- The significance of incorporating pain and fatigue functional domains to ensure the inclusion of older persons.

Not all functional domains were included; five out of six domains from the short set were used, along with four additional domains from the extended set.

### Prevalence Findings:

The Washington Group questions proved highly effective in screening for mental health conditions such as anxiety, depression, and fatigue, as well as disabilities related to intellectual functioning, vision, mobility, and pain. However, they were less effective in identifying hearing impairments.

While the questions successfully assessed “invisible” disabilities, such as those linked to mental health, they appeared less accurate in capturing certain “visible” disabilities, including hearing impairments.

It is important to recognize that these questions are only one component of the assessment process, with outcomes potentially influenced by factors such as data collection methods, sampling approaches, and response biases.



## Barriers and Enablers

Persons with disabilities and older adults face specific barriers in humanitarian settings that increase their risks by exacerbating existing threats and vulnerabilities. These barriers can be attitudinal, environmental, or institutional.<sup>25</sup> While barriers impede access to humanitarian assistance, enablers provide mechanisms that facilitate such access. Importantly, enablers contribute to improved individual resilience within humanitarian contexts.<sup>23</sup>

Data and evidence are crucial for understanding and addressing the barriers and enablers that persons with disabilities and older adults encounter. Inclusive data collection is highlighted as one of the key actions in the IASC Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action.<sup>23</sup>

SIRA (Survey for Inclusive Rapid Assessment) was developed to assess existing barriers and enablers both across all respondents and within specific groups, utilizing sex-, age-, and disability-disaggregated data. This dual approach is justified not only by the logistical considerations of data collection with random samples but also by the objective of supporting both mainstreaming and targeted strategies for inclusion in humanitarian action.

Assessing barriers and enablers goes beyond a simple health-focused assessment of disability. Therefore, this dual approach can be effectively implemented within SIRA to provide a more comprehensive understanding of inclusion in humanitarian settings.



## Barriers and Enablers

Key learnings from SIRA in the Data that Matters project:

- **Disability-mainstreaming:** many key barriers and enablers were common to persons with and without disabilities and persons of different ages and both sexes. Common strategies and responses that are inclusive should be implemented.
- **Targeted approach:** some barriers, and enablers were specific to persons with disabilities and older persons – e.g. around physical accessibility of WASH facilities, and transportation for persons with disabilities.
- **Key barriers and enablers expressed at household level:** assessment was also conducted at individual level, but responses always encompassed a wider dimension that is common to the household unit. To assess a specific target group only, Focus Group Discussions may offer complementary means for assessing target group-specific responses.



## Qualitative and Quantitative Data

Mixed methods enable the characterization of patterns and trends at an aggregate level through quantitative questions, while qualitative questions probe the non-linear processes accounting for these observed patterns and trends within a population. Qualitative data provides a better understanding of individuals' lived experiences.

The Survey for Inclusive Rapid Assessment (SIRA) is a mixed-methods survey that combines both quantitative and qualitative questions. The quantitative component of SIRA centers on the Washington Group questions, as well as household and individual socio-demographic characteristics such as education level and household size. The qualitative component is divided into one structured and one unstructured set of questions. The structured qualitative questionnaire uses a predefined list of barriers used by the International Organization for Migration's Displacement Tracing Matrix tool as developed with UNHCR, UNICEF and Humanity & Inclusion.<sup>18</sup> This structured information focuses on the processes underpinning existing barriers. The unstructured qualitative questions focus on enablers and the individual respondent's experiences.

Overall, in addition to key demographic information at the individual and household levels, SIRA aims to capture both the subjective experiences and the needs of individuals. This is all achieved within the scope of a rapid assessment tool that is straightforward to deploy and uses simple language.

### **Why does SIRA leverage qualitative methods to capture the lived experiences of individuals, particularly persons with disabilities and older adults?**

Limitations in effectively using disability prevalence and functional ability data for programme planning and implementation have been extensively reported.<sup>7</sup>

Although the Washington Group Questions can identify functional impairments associated with key domains, they are not intended to capture the subjective experience of having a disability or self-identifying as such.<sup>13</sup>

Similarly, understanding the needs of older adults - and how these may differ from those of younger individuals and persons with disabilities - is more effectively achieved through their own voices. Personal narratives providing deeper insights into their unique experiences and challenges.

In designing SIRA, the Data that Matters project applied human-centred design principles to characterize the data needs of diverse stakeholders. The co-creation activities conducted emphasized the importance of individual narratives in understanding the non-linear processes that affect access to humanitarian assistance.



## Human-Centred Design (HCD) Approach

Human-centred design (HCD) is an approach to problem-solving that put people, their context and experience at the heart of the process. HCD methodology uses an empathetic mindset, active listening, and participatory approaches to deeply understand the needs of people. When applied through a lens of diversity and inclusion, HCD becomes a powerful tool for addressing the diverse needs and challenges faced by persons with disabilities, whether physical, sensorial, psychosocial, intellectual, or multiple.

As part of the design of a rapid assessment SIRA tool, human-centred design research was conducted with persons with disabilities and older persons living in IDP (internally displaced people) camps in Cabo Delgado, Mozambique. Information was collected on their needs, barriers, interests, capabilities, and their experiences while living at the camp, and when being interviewed by data collectors. The results and learnings gathered were used as a starting point for generating ideas and recommendations for the development of the SIRA Tool.

When applying human-centred design, an open mindset is necessary to move away from preconceived beliefs and assumptions and make space for unexpected insights. Deeply understanding another person requires us to step into someone else's shoes and uncover new ways of seeing. To do that, you should consider the following:

- **Empathy:** Having an empathetic and curious mindset will allow you to see through the eyes of the people you are designing for and understand reality from their perspective.
- **Participatory tools:** participatory tools are useful since they allow the persons to take an active role during a data collection process or interview. With participatory tools, interviewees can apply creative ways to explain their point of view that are outside of the box, resulting in unexpected outcomes.
- **Active listening:** when approaching persons in your research, practice active listening to truly be open to listen without interruptions or assumptions.
- **Ask in-depth questions:** when in doubt about the meaning of certain answers provided by interviewed persons, take the time to dig deeper and ask why.
- **Validate conclusions:** It is essential to have an open-mind and move beyond assumptions and fast conclusions. You may choose to validate your conclusions with more persons that experience similar challenges.
- **Co-creation:** A successful strategy is to co-create your data collection questionnaire with people with disabilities and involve actively as enumerators in the process and when analysing and drawing conclusions. They are most equipped to provide adequate advice for developing an inclusive data collection process.

## How to use the SIRA Tool

SIRA is a digital data collection tool consisting of household and individual questionnaires aimed at identifying the barriers and enablers that persons with disabilities and older adults face in accessing humanitarian assistance.

- The household questionnaire focuses on demographic information such as the characteristics of the household head, household size, and displacement status.
- The individual questionnaire covers additional socio-demographic characteristics - including health status, education level, and income - as well as the Washington Group Questions and inquiries about the barriers and enablers experienced.

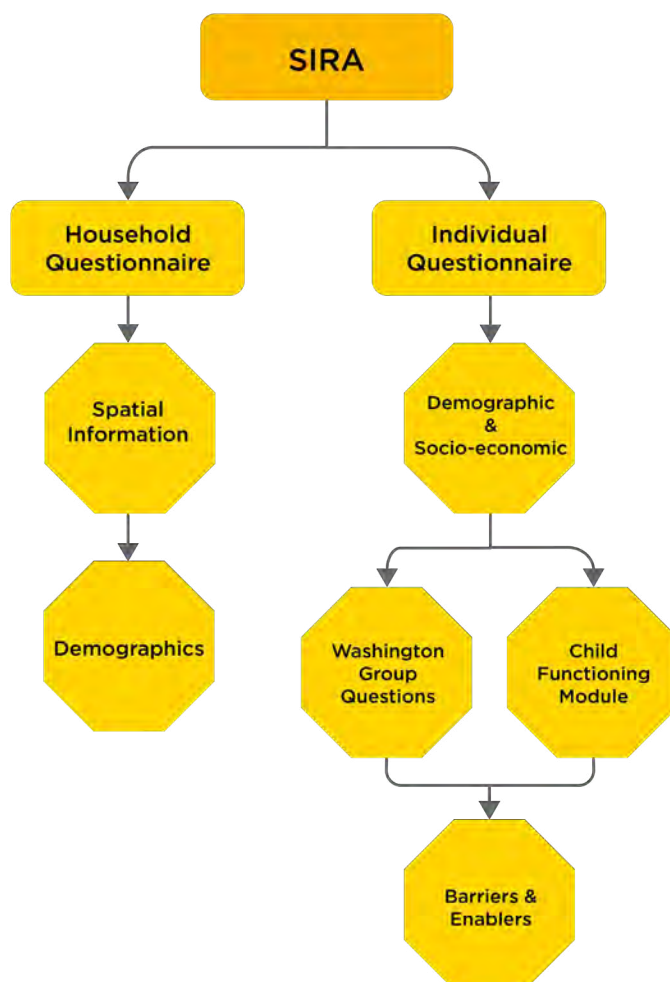
Although SIRA was initially designed to survey both persons with and without disabilities across all age groups, it can also be deployed with specific target groups, such as older adults only. It has been tested using two-stage stratified sampling as well as during focus group discussions.

Importantly, SIRA was designed based on a modular structure, allowing the tool to be adapted to the specific context of a given humanitarian programme. SIRA needs to reflect the intervention logic when assessing barriers and enablers. For example, in its current form, SIRA focuses on barriers and enablers in accessing:

- All types of humanitarian distributions and services
- Different livelihood opportunities
- Sexual and reproductive health services
- Personal safety and security

These focus areas are the result of desk research and human-centred design activities conducted in Cabo Delgado, Mozambique. However, for a WASH (Water, Sanitation, and Hygiene) programme, for instance, questions on distribution, services, and safety should be specific to WASH aspects, while additional questions on livelihood and sexual and reproductive health may be omitted.

SIRA's flexibility is aimed at keeping the tool adaptable, ensuring it can support disability- and older age-inclusive rapid needs assessments in diverse contexts.



## Training of Enumerators

### Training Strategies for Enumerators

**Although SIRA was not specifically designed to be implemented solely by persons with disabilities and older adults, the aim of the Data That Matters project was to develop a simple tool that could also be deployed by community-based organizations - particularly Organizations of Persons with Disabilities (OPDs) and Older Persons' Associations (OPAs).**

To ensure effective use of the tool, the following training strategies have been employed:

- 1. Interactive Introductions:** Begin with a round of introductions to understand the backgrounds of the enumerators. This helps identify individuals who can support others and serves as an ice-breaker to build team cohesion.
- 2. Diverse Group Formation:** Create groups mixing young and older persons, individuals with and without disabilities, locals from the survey area and those from outside, as well as a balance of women and men. This diversity promotes peer support, making the training more accessible through shared experiences in technology use, language proficiency, and reasonable accommodations.
- 3. Comprehensive Training Modules:** Cover topics on disability and older-age inclusion in humanitarian action and survey methodologies through a blend of theoretical instruction and practical exercises. This ensures that enumerators are well-versed in both the conceptual and operational aspects of the survey, and are comfortable with asking and recording qualitative questions.
- 4. Digital Tool Setup and Testing:** Assist enumerators in setting up email accounts, accessing data collection software, and using tablets or smartphones. Include training on accessibility features such as screen-reader compatibility and high-contrast settings to accommodate various needs.
- 5. Language Translation and Sensitivity:** Conduct reverse and double translations of survey content into local languages. This step is crucial to avoid stigma, ensure cultural sensitivity, and maintain data quality.
- 6. Role-Playing and Scenario Practice:** Engage enumerators in extensive role-playing exercises that simulate diverse scenarios - including linguistic challenges, demographic variations, different types of disabilities, and geographic orientations - to prepare them for real-world data collection.
- 7. Field Testing:** If possible, conduct a pilot field test prior to the actual survey to ensure all aspects are functioning as planned and to provide enumerators with hands-on experience.

### Strategies to Overcome Challenges

- 1. Identify and Empower 'Champions':** Recognize individuals within the group who exhibit strong understanding and leadership qualities to act as peer mentors. These champions can guide and assist others in using tools and methodologies.



## Training of Enumerators

2. **Tailored Communication:** Adapt training materials and communication methods to suit different age groups and educational levels. Use simple language and visual aids to enhance understanding.
3. **Hands-On Technology Training:** Provide step-by-step guidance on using tablets and digital tools, starting from basic operations to more advanced functions. Allow ample time for practice.
4. **Assistance in Setting Up Emails:** Facilitate the creation of email accounts for those who do not have them, ensuring everyone has equal access to digital resources.
5. **Foster Inclusive Environment:** Encourage patience, empathy, and mutual respect among enumerators to create a supportive learning atmosphere.

## Tips and Tricks for Enumerators

- **Work in Pairs:** Always walk in pairs, preferably with organizational attire, to ensure visibility and credibility. This helps respondents recognize that you are officially conducting a survey on behalf of an organization.
- **Carry Authorization Documents:** Have copies of permits or letters from community leaders indicating approval to conduct the survey in the area. If possible, keep a voice recording or video message on your phone from community leaders expressing their support.
- **Respect Household Dynamics:** Ask the household members whom they prefer to start the interview with. Ensure that respondents understand why certain parts of the survey, such as the Washington Group Questions, need to be asked to other household members.
- **Communicate the Survey's Value:** Explain the benefits of the survey to the community, emphasizing how understanding the situation of a randomly selected sample can lead to improved humanitarian assistance for everyone.
- **Cultural Sensitivity:** Be mindful of local customs, traditions, and social norms. Approach sensitive topics with care and use culturally appropriate language.
- **Stay Safe and Aware:** Be vigilant of your surroundings and prioritize personal safety. If an area feels unsafe, do not proceed without assessing the risks.
- **Maintain Confidentiality:** Assure respondents that their information will be kept confidential and used solely for the purposes of research, advocacy and improving humanitarian programming.
- **Effective Communication and Reasonable Accommodation:** Use clear and simple language. If there are language barriers, consider working with a local interpreter or community liaison. This is particularly important when persons with hearing impairment do not speak formal sign language. Ensure reasonable accommodation can always be provided.
- **Logistical Preparedness:** Ensure all equipment is fully charged and functioning before heading out. Carry necessary supplies like notepads, pens, and backup batteries.
- **Debrief Regularly:** After each day of data collection, debrief with your team to discuss challenges faced and share insights. This can help improve strategies for subsequent days.

## Analysis of Data

SIRA ensures that sex, age, and disability disaggregation is available for all survey respondents. Its design - guided by human-centered design principles and extensive research - incorporates the Washington Group psychosocial functional domains, which should be included in all analyses and in estimating disability prevalence. We recommend using a cut-off threshold of 50 years to define older age,<sup>26</sup> as humanitarian and emergency settings are expected to be challenging.

Disaggregation allows for the comparison of household and individual characteristics of persons with disabilities and older persons to the average or median profiles in the data and/or other groups.

The analysis of SIRA results focuses on the barriers and enablers that individuals face in accessing humanitarian assistance. SIRA supports a twin-track approach, where assessing needs and access can inform both disability and older-age mainstreaming strategies, as well as targeted approaches for inclusion. For example, targets for disability mainstreaming can be identified by analysing common barriers and enablers between respondents with and without disabilities. Conversely, barriers and enablers specific to persons with disabilities highlight priority areas for targeted interventions.

SIRA is a survey tool intended for both large-scale data collection and smaller settings such as focus group discussions. In large-scale surveys, significant volumes of narrative, qualitative information may be collected. Generative artificial intelligence (AI) tools can be used for the analysis of this data, provided that the tools employed safeguard the underlying data.

### Best Practices for Data Analysis

#### A) Quantitative Data Analysis

- Calculate Prevalence Using Washington Group Questions (WGQ)
- Assess Functional Domains' Contributions: Analyse the relative contribution of each functional domain - or set of WGQ - to the overall prevalence estimate.
- Examine Age-Related Functional Domains: Investigate how certain functional domains are associated with age, focusing on areas like pain, psychosocial well-being, and mobility. This analysis can reveal important trends.

#### B) Qualitative Data Analysis

- Leverage AI Models for Unstructured Data: Utilize question-answering AI models to analyse unstructured qualitative data on enablers collected through SIRA. These models can efficiently process large volumes of text, extracting key themes and insights.
- Segment Data Using Disaggregation: Before analysing qualitative data with AI tools, segment the data based on socio-demographic factors such as sex, age, disability status, and displacement status. Disaggregating the data ensures we can investigate how different groups experience barriers and enablers.

## Analysis of Data

### C) Interactive Analysis Tools

- **Employ Interactive Dashboards:** interactive analysis tools are highly effective for rapidly exploring data from SIRA. They enable users to segment and visualize data based on various socio-demographic characteristics, such as sex, age, disability, and displacement status. These tools support dynamic querying and real-time visualization, making data exploration more intuitive and accessible. An example of interactive dashboard used for analysis of SIRA results can be found in the [SIRA Dashboard](#).

### Additional Tips

- **Maintain Ethical Standards:** when using AI tools, ensure that data privacy and confidentiality are maintained. use secure platforms or open-source tools that comply with data protection regulations to safeguard sensitive information.
- **Capture emergent knowledge with those involved in data collection:** engage with team members and stakeholders throughout the analysis process. their insights can provide valuable context and help interpret findings more effectively (see chapter 2, pp. 11-31).







# 4

## **Disability and Older Age- inclusive Data for Advocacy, Humanitarian Programming and Referrals**

## Data for Advocacy

Advocacy for inclusive humanitarian action aims to achieve equal access of all to protection, safety and assistance.

Article 11 of the UNCRPD<sup>21</sup> states that **all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.**

Advocacy for inclusive humanitarian action may target:

- Community leaders
- National Government of affected area
- UN agencies, INGOs and NNGOs
- Donors – including governments

**Advocacy is about influencing systems change and may aim for long-term outcomes.** Inclusive data does not by itself lead to better inclusion outcomes. It can however support advocacy efforts to support these outcomes.

An inclusive data ecosystem can support the effective and meaningful participation of affected populations in humanitarian action. Involving representative organizations like Organizations of Persons with Disabilities (OPDs) and Older Persons Associations (OPAs) can facilitate this engagement. Ideally, this would lead to these organizations and other local actors taking full ownership of the data generation process and spearheading evidence-based advocacy efforts.

Inclusive data for advocacy to:



**National Governments, affected areas**



**UN agencies, INGOs, NNGOs**



**Donors, including governments**

## Data for Advocacy – National Government of Crisis-affected Country

### Key Learnings

- ◆ **Data as evidence for advocacy:** data plays a crucial role in providing evidence to support advocacy efforts.
- ◆ **Transparency and quality enhance credibility:** transparency, coupled with high-quality data and methodologies, strengthens the credibility of advocacy initiatives.
- ◆ **Centralized and secure data systems:** establishing a centralized local database or cloud system with secure digital data collection is important for effective data management.
- ◆ **Leveraging government connections:** when possible, utilize strong connections between the humanitarian cluster system and government agencies to bolster advocacy work.
- ◆ **Reputation matters:** the advocating organization's reputation significantly impacts the success of advocacy efforts.
- ◆ **Importance of local champions:** engaging local champions within relevant ministries and agencies is key to advancing advocacy goals.
- ◆ **Building alliances:** finding allies to support the advocacy effort is essential for amplifying impact.
- ◆ **Encouraging government action:** it is important to push the government to address and act upon the identified barriers.

### Recommendations

- ◆ **Ensure data safeguarding:** fully anonymize all data to prevent the re-identification of individuals in crisis-affected areas, thereby protecting their privacy and safety.
- ◆ **Use secure data-sharing platforms** like UN-OCHA's Humanitarian Data Exchange (HDX) to share and manage data securely, supporting data safeguarding efforts.
- ◆ **Identify government advocacy entry points:** find effective avenues to engage with the government for advocacy, enhancing the impact of your initiatives.
- ◆ **Develop a data action plan with government buy-in:** create a comprehensive action plan for data management and ensure it has government support to facilitate successful implementation.
- ◆ **Promote government ownership** of data initiatives to strengthen commitment and ensure long-term sustainability.
- ◆ **Aim for high-level government engagement:** seek buy-in from top government officials to enable a trickle-down effect of support throughout all levels of government.
- ◆ **Review and enhance data collection practices:** conduct thorough reviews of data collection methods. when assessing the role of civil society in data collection, offer tools, data, and step-by-step guides to support their involvement.



## Data for Advocacy to UN Agencies, INGOs and NNGOs

### Key Learnings

- ◆ **Engage Local Champions:** Involving local champions within relevant organizations is crucial for effective advocacy.
- ◆ **Find Allies:** Identifying and collaborating with allies strengthens advocacy efforts. Leverage INGOs for Data Analysis: International Non-Governmental Organizations (INGOs) can support data analysis and assist in crafting response and action points.
- ◆ **Leverage the Protection Cluster:** The Protection Cluster serves as a key platform for sharing evidence, findings, and advocacy messages.
- ◆ **Establish Disability Working Groups:** Working with or establishing a disability working group within the Protection Cluster is an effective mechanism for advocacy.
- ◆ **Focus on Humanitarian Programming and Resource Mobilization:** Advocacy at this level focuses on humanitarian programming - such as service delivery - and resource mobilization, including funding.
- ◆ **Use Disability Prevalence Data:** Disability prevalence data, along with the methodologies used to collect it, is important for advocacy messaging to UN agencies and NGOs.
- ◆ **Assess and Share Psychosocial Disability Data:** Psychosocial disability (mental health) data is crucial and should be assessed and shared for advocacy purposes.
- ◆ **Raise Awareness on Psychosocial Disabilities:** Raising awareness about the integral role of psychosocial disabilities among disability types is necessary, requiring action based on humanitarian principles and the UN Convention on the Rights of Persons with Disabilities (UNCPRD).<sup>21</sup>



## Data for Advocacy to UN Agencies, INGOs and NNGOs

### Recommendations

- ◆ **Empower local organizations:** place representative organisations - such as OPDs and OPAs- in leadership roles for data collection and coordination mechanisms.
- ◆ **Utilize psychosocial functional domains** when using the Washington Group questions and estimating disability prevalence
- ◆ **Identify and share findings on barriers and enablers** persons with disabilities and older persons face in accessing humanitarian assistance.
- ◆ **Leverage advocacy opportunities:** utilize key documents like the humanitarian needs analysis and the humanitarian response plan to strengthen advocacy efforts.
- ◆ **Develop a data action plan:** create a comprehensive action plan for data management, including data sharing strategies and communication of findings.
- ◆ **Utilise open data standards and platforms** such as UN-OCHA's Humanitarian Data Exchange (HDX) to promote collaboration and ensure secure data sharing.
- ◆ **Ensure data safeguarding:** fully anonymize data to prevent re-identification of individuals in crisis-affected areas.





## Data for Advocacy to Donors – Including Governments

### Key Learnings

- ♦ **Engage local champions:** involving local champions within relevant organizations is crucial for successful advocacy efforts.
- ♦ **Find allies:** identifying and collaborating with allies strengthens and supports advocacy initiatives.
- ♦ **Utilize relevant platforms and forums:** leveraging appropriate platforms and forums enhances the effectiveness of advocacy efforts.
- ♦ **Recognize short-term and long-term goals:** advocacy should address both immediate and future objectives.
  - Long-term goals: aim for normative changes in funding policies and frameworks.
  - Short-term goals: focus on securing funding to meet immediate needs identified in crisis settings.
- ♦ **Advocate at multiple levels:** engaging in advocacy at international/multilateral, national/agency, and local/representation levels can increase overall impact.
- ♦ **Leverage key supporting documents:** crisis assessments and humanitarian response plans are essential when advocating to donors through the UN system.

### Recommendations

- ♦ **Partner with representative organisation for valuable insights:** to gain first-hand knowledge of the specific challenges faced by target groups -such as persons with disabilities and older persons. This partnership amplifies impact by ensuring that affected populations are not only beneficiaries but also active agents of the humanitarian response.
- ♦ **Hold donors accountable using data and legal obligations:** leverage data and evidence to hold donors accountable based on legal obligations outlined in the UN Convention on the Rights of Persons with Disabilities (UNCRPD), specifically articles 11 (humanitarian situations), 31 (statistics and data collection), and 32 (international cooperation).
- ♦ **Institutionalize data collection in funding requirements:** advocate for the inclusion of data collection and disaggregation mandates in funding requirements to ensure organizations systematically collect data on disability and older age.
- ♦ **Engage in-country donor representatives:** reach out to donor representatives within the country to indirectly advocate to UN agencies and national governments in crisis-affected areas.
- ♦ **Utilize crisis assessments and response plans:** employ crisis assessments and humanitarian response plans that include disability and older-age relevant data as tools in advocacy efforts directed at donors.



## Data for Inclusive Humanitarian Programming

Data plays a crucial role in every step of the Humanitarian Programme Cycle by providing evidence that informs decision-making. The sources of this data are varied and context-dependent, encompassing both primary data collected firsthand and secondary data from existing sources.

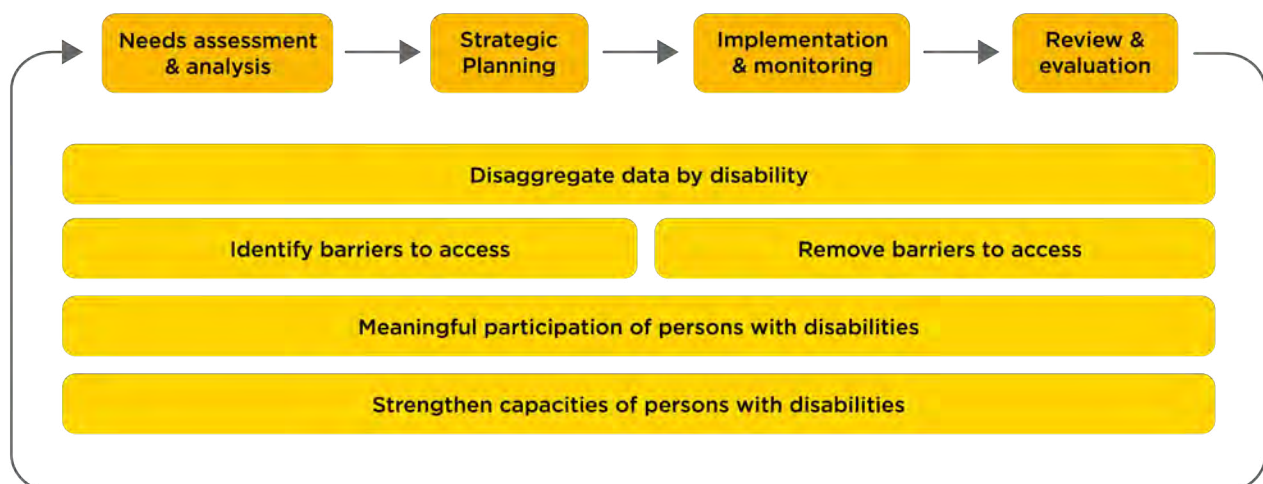
To achieve full inclusivity, according to the IASC Guidelines on the inclusion of persons with disabilities, humanitarian action must:<sup>23</sup>

- Disaggregate data by disability
- Identify and remove barriers to access
- Ensure meaningful participation of persons with disabilities
- Strengthen the capacity of persons with disabilities

SIRA supports these four essential actions. SIRA is a primary data collection tool that can be utilized throughout the programme lifecycle. It assesses the barriers and enablers individuals face in accessing humanitarian assistance, particularly focusing on persons with disabilities and older persons. To remain relevant in humanitarian programming, questions about barriers need to be adapted to reflect the specific implementation strategy - for example, tailoring them to sectors like Water, Sanitation, and Hygiene (WASH). Because barriers and enablers may change throughout the programme cycle, SIRA can be used multiple times during implementation. For instance, pre-disaster data may not capture the full extent of the specific needs of people with disabilities after a disaster.<sup>27</sup>

As a rapid assessment tool, SIRA is suitable for implementation during most stages of the crisis response cycle. The notable exception is at the onset of a crisis, due to SIRA's partial focus on service mapping for referrals and the meaningful participation of persons with disabilities.

### Humanitarian Programming Cycle



## Data for Inclusive Humanitarian Programming

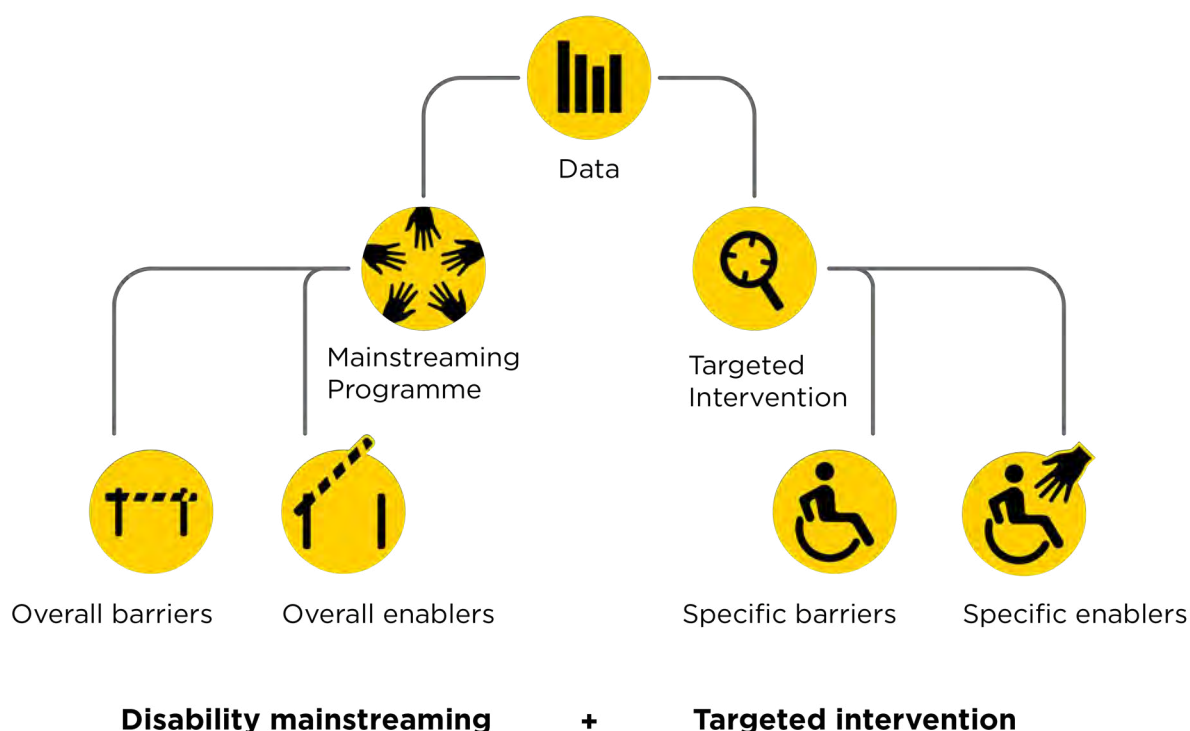
### Twin-track Approach

To achieve inclusive humanitarian action, efforts should focus on a twin-track approach that combines inclusive mainstreaming programmes with targeted interventions aimed at including persons with disabilities and older individuals.<sup>23 25</sup>

SIRA supports both disability mainstreaming and targeted interventions. SIRA evaluates the barriers and enablers that individuals face in accessing humanitarian assistance. This assessment supports programme interventions and efforts to mainstream disability.

Integrating disability into programmes ensures that humanitarian assistance - including distributions, services, and processes - is accessible to everyone, including persons with disabilities. Applying universal design principles is one way to achieve this.

By disaggregating data by sex, age, and disability, SIRA assesses the specific barriers and enablers that persons with disabilities and older individuals face. By identifying these particular barriers and enablers, SIRA facilitates evidence-based, targeted interventions. These targeted interventions aim to remove the identified barriers, and the solutions may ultimately benefit everyone.



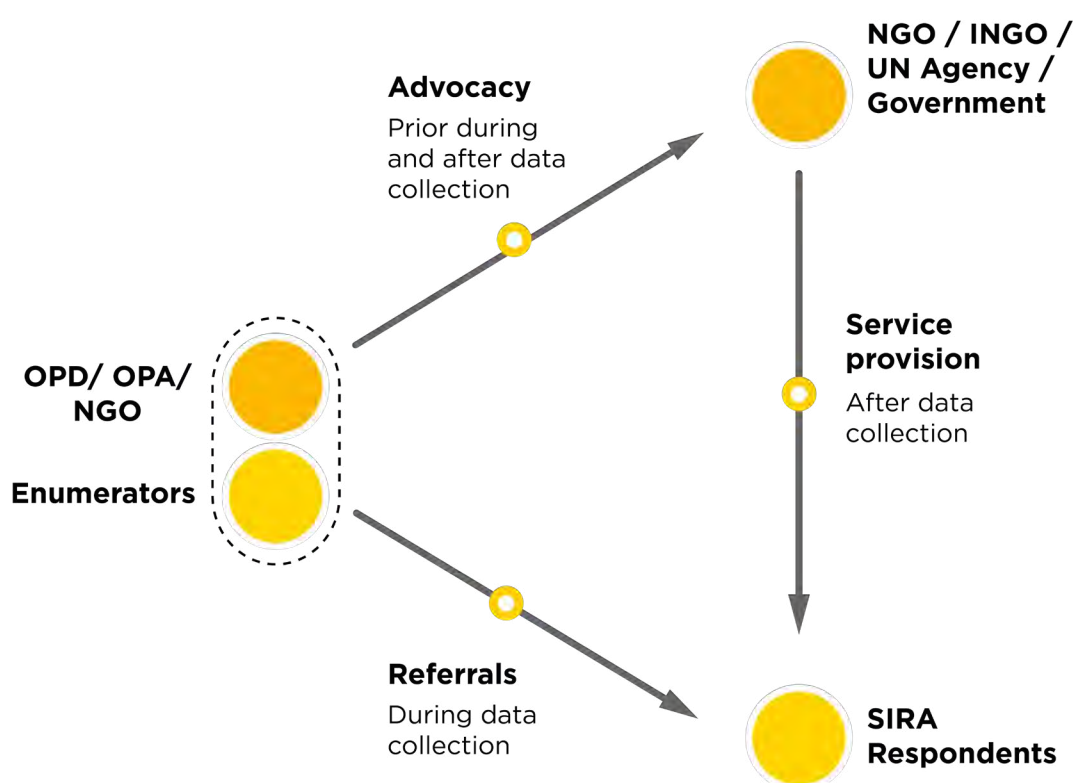
## Data for Referrals

Providing assistance to individuals in need is an obligation. When an organization or individual cannot offer specific help, referring them to other organizations can fulfil that responsibility. Data collection presents a key opportunity to provide such referrals to respondents, ensuring the process is not solely extractive but also delivers immediate benefits.

By mapping existing services and organizations in the survey area prior to data collection, SIRA facilitates the provision of referrals to individuals at the end of each interview. SIRA's questions on barriers and enablers, along with disaggregation by sex, older age, and disability, ensure that specific referrals can be tailored to each respondent. The list of available services and service providers in the target area can be obtained beforehand from humanitarian cluster leads.

Providing referrals helps to balance the extractive nature of data collection by offering tangible benefits to survey respondents. This practice also strengthens the ethical foundation of data collection by ensuring that participants receive a beneficial outcome from their involvement.

Referrals can be directed to specific services and organizations that adopt a disability-inclusive approach. Informing these organizations that persons with disabilities are being referred to them facilitates better assistance and support. This communication opens opportunities for conducting training and capacity-building within the organization, as well as for raising awareness, to make their services more accessible to persons with disabilities.





## Data for Referrals

Organizations of Persons with Disabilities (OPDs), Older Persons Associations (OPAs), local organizations, and specialized NGOs can play an advisory role in promoting disability and older-age inclusion. They can offer training on inclusion to the organizations receiving referrals or engage in awareness-raising activities to enhance accessibility.

Humanitarian services are mapped by the coordinating unit or cluster lead through a systematic process of collecting and consolidating information from all participating organizations. They gather data on who is providing services, what activities they are conducting, where these services are located, and for whom they are intended (often referred to as the “4Ws”). This information is compiled into service mapping matrices or maps, which are regularly updated and shared among stakeholders. These maps and matrices should be used for planning referrals.



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## Notes

- i. FAMOD: Fórum das Associações Moçambicanas das Pessoas com Deficiência, the Mozambican national umbrella body of organizations of persons with disabilities.
- ii. The interactive dashboard can be found at [n-merlaint.shinyapps.io/Analysis\\_Dashboard/](https://n-merlaint.shinyapps.io/Analysis_Dashboard/)
- iii. Statistical Disclosure Control: a set of techniques and methods used to protect the confidentiality of individuals or entities in microdata and aggregated data before it is shared or published. The goal of SDC is to prevent the identification of specific individuals or units within a dataset, reducing the risk of privacy breaches while allowing valuable data to be released for research and analysis.
- iv. The Data that Matters project repository can be found at <https://github.com/nadir-AS/DTM>.
- v. [IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action \(2019\).](#)



# Want to Know More?

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