

Final Report

Desk Research: Data That Matters (Phase 3)

Light for the World



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Introduction

The purpose of this report is to provide desk research for the project Data That Matters, in support of Light for the World's ongoing work in Cabo Delgado, Mozambique. The Desk Review will contribute to the important work in Mozambique by helping to further understand disability assessment data gathering and decision-making through the development of a mixed-method rapid assessment tool.

This desk research has three objectives:

- Map existing data collection methods and their previous use to collect data on persons with disabilities and/or older people in the Cabo Delgado humanitarian context in Mozambique
- Map existing scientific and grey literature on identification and assessment of persons with disabilities and/or older people, with a clear focus on humanitarian settings (enablers/barriers)
- Map usage of mixed-methods (combined qualitative and quantitative) in inclusive planning, programming and/or policy-making with a focus when possible on a humanitarian and/or development context.

This desk research will answer three research questions:

- What data collection methods (quantitative and/or qualitative) have been used in the humanitarian context of Cabo Delgado? Of these, which/how was data on persons with disabilities and older persons captured? To what extent does the resulting data assess the existing barriers and enablers for persons with disabilities and older persons to access humanitarian assistance?
- With a focus on humanitarian action, what is the current state-of-the-art in identifying and assessing persons with disabilities and older persons? To which stages of a humanitarian response are these methods and approaches relevant? Are the methods applicable in diverse humanitarian contexts?
- What is the current state-of-the-art on using mixed-methods tools and approaches for disability-inclusive planning, programming, and/or policy?

To that end, Fora Education has conducted a literature review of over 40 reports and research articles and 7 key informant interviews (KIIs) consisting of 6 working directly in the Cabo Delgado setting and 1 with knowledge and expertise in disability identification and assessment in humanitarian settings. In the report below, we will answer each research question in turn.

A short case study is included of the use of Washington Group Short Set questions to understand disability and connection to services and interventions that was used by a project in Bhutan headed by Fora Education CEO and Founder, Matthew Schuelka.

In the Appendix, we will include the entire bibliography of the literature review, as produced by Zotero. All literature materials will be provided in a separate file.

It should be noted that in our extensive literature search and other data collected, there was little mention or disaggregation of older persons as a specific disadvantaged group beyond including age in the survey or questionnaire. In many ways, older persons will significantly overlap with persons with disabilities of any age in terms of physical and mental challenges related to access, inclusion, and functioning (Akerkar & Bhardwaj, 2018), but there are specific age-related issues such as nutrition, communication, and childcare responsibilities that should not be overlooked when considering older persons in humanitarian settings (Karunakara, 2015). We also believe that a rapid assessment tool should identify and assess the functional capability of an *individual at any age* and direct them towards appropriate humanitarian services. Thus, in the report below much of the discussion of literature will be from a disability-inclusion perspective that can be assumed to include older persons with similar challenges. There is a specific section in regard to older persons within Research Question 2.

Research Question 1

What data collection methods (quantitative and/or qualitative) have been used in the humanitarian context of Cabo Delgado? Of these, which/how was data on persons with disabilities and older persons captured? To what extent does the resulting data assess the existing barriers and enablers for persons with disabilities and older persons to access humanitarian assistance?

In order to answer this question, we conducted 7 KIIs and a literature review. The direct answer to this research question is:

- Data collection methods for persons with disabilities that have been used in Cabo Delgado include surveys, key informant interviews (KIIs), and focus group discussions (FGDs).
- Data has been captured using the Washington Group Questions Short Set (WGQ-SS) questionnaire as well as qualitative approaches to understanding the challenges that persons with disabilities face.
- Barriers and enablers that persons with disabilities face in accessing humanitarian assistance were specifically collected by the International Organization for Migration (IOM) with assistance from FAMOD.
- Older persons were not specifically targeted in any data collection method.

- Other rapid assessments have been conducted by UN OCHA through the MIRA tool (IASC, 2012), and several other humanitarian organizations (ACTED, 2023).
- There is a centralized database, HDX, maintained by UN OCHA that does have some disability information (Light for the World, 2022), but was not widely known or mentioned specifically by KIs.

At the moment, the level of data collection in Cabo Delgado has been at the census-taking level that has been undertaken by several organizations, particularly the UN humanitarian cluster. It was reported that surveys have been conducted using Kobo Toolbox, for example. FAMOD – the umbrella OPD organization working in the area – has a basic demographic collection process for maintaining a database and reports that the OPDs generally work with referrals or known persons with disabilities in the community. Project Connect also works on the ground in Cabo Delgado and has a collection tool as well, and CBR programs use disability identification tools and criteria to assess intervention suitability and CBR plans. Both FAMOD and Project Connect work directly with OPDs and community leaders to gather information. Data specific to older persons was not mentioned at all by any of our KIs or from the literature. Fora Education did not have access to these tools and collection methods directly, and these were reported to us via the KIs only.

According to our key informants, there are currently issues in collecting data on persons with disabilities that include missing persons with less ‘visible’ disabilities, the absence of one single database that is shared amongst organizations or widely known and shared, little capacity of the government; and the lack of any official disability identification, assessment, and certification policy from the government. The services provided by the Mozambique government were reported to be absent or overwhelmed. On the database point, there is a database that is run by United Nations Office for the Coordination of Humanitarian Affairs (UN OCHA), HDX (<https://data.humdata.org>), that does contain some centralized information, including a disability dataset collected by Light for the World (2022).

It was also revealed through KIs and feedback that the UN OCHA has a rapid assessment tool for humanitarian settings called Multi-Cluster/Sector Initial Rapid Assessment (MIRA) (Inter-Agency Standing Committee, 2012) that FAMOD has participated with in Cabo Delgado. The complete MIRA tool and reporting templates is included in the attached files and bibliography (Inter-Agency Standing Committee, 2012) and includes disability-inclusion-related questions. While the initial MIRA for

Cabo Delgado itself cannot be accessed online, we were able to find a report from ACTED (2023) that synthesized the findings from the MIRA, a rapid assessment from several humanitarian organizations (Solidarites International et al., 2022), and a UN Protection Cluster rapid assessment. There is some mention of disability in the ACTED (2023) report, including this passage:

Protection concerns and the lack of help for disabled people was also highlighted by the women in focus group discussions. Women with disabilities have difficulty in moving around to seek means of subsistence for their families, especially those who have become female heads of household because they lost their husbands during the conflicts and have no assistance (housing, food, among others). A safety audit should be carried out with community members to better identify their protection needs. There is no known case management ongoing at this time. (p. 13)

These kinds of rapid assessment tools such as the MIRA and database sets such as the HDX contain disability information but are generalized and at the population level rather than at the specific individual support level.

FAMOD and Project Connect do provide linkages to humanitarian services as a result of their data gathering. However, they report that while the humanitarian services in the area are known, the challenge is *gaining access* to these already-known services. For example (as recorded in KII):

“Communication: Hearing impaired person going to get assessment but person doing assessment doesn’t speak sign language.

Transportation: Public transport very difficult for person with wheelchair they do not accept - they charge the person and the wheelchair.

Education: Lack of accessibility, school infrastructure isn’t accessible. Curriculum materials and teaching methodology is not there for person with a disability. Lack of instruction; there are not teachers who will teach students with visual and hearing impairment - don’t know Braille or sign language.

WASH: barrier of community and accessibility reaching those services, ramps are there but not the correct angle so it is a barrier and nobody can speak sign language.

Employment: Main challenge is attitude problem. Employers think person with a disability are incapable to any task in the company. Employers think: How will this person bring a gain to our organization? Add value to our company? They see them as a burden. Companies who employ person with a disability see it as a charity.”

The most significant study that we have found regarding data on persons with disabilities in Cabo Delgado was conducted by the International Organization for Migration (IOM) (2022). In order to assess and understand the current situation for persons with disabilities in Cabo Delgado, IOM conducted a survey of nearly 2,000 consenting adults from nearly 650 randomly-selected households. In the survey, the Washington Group Questions Short Set (WGQ-SS) questions were used to self-report functionality in 6 domains:

- a) Seeing (even If wearing glasses);
- b) Hearing (even if using a hearing aid);
- c) Walking or climbing steps;
- d) Remembering or concentrating;
- e) Washing or dressing;
- f) Communicating in one's customary language or being understood.

The IOM reports some issues and anomalies with the WGQ-SS data, but details were not given. Key informant interviews (KIIs) and focus group discussions (FGDs) were also conducted. Nine KIIs were conducted, primarily with officials, and 10 FGDs were conducted, primarily with persons with disabilities themselves.

The IOM reports that the disability prevalence rate in Cabo Delgado is 15%, although that number is somewhat unsure according to their own reporting. In the methodology section of the IOM report, the disability prevalence rate is given as a 'best-guess' and they indicated that there were 'discrepancies in the data' but did not elaborate. Therefore, there is a need for a better rapid assessment tool and better data specific to disability-inclusion in the Cabo Delgado region of Mozambique.

According to the 2022 IOM report, the following barriers were reported through the data:

- Difficulty in reaching distribution points
- Access to sanitation facilities and latrines
- Access to water collection points
- Access to shower and WASH facilities
- Access to education
- Difficulties in participating in cultural activities
- Access to healthcare services
- Difficulties in entering and living in shelters
- Access to markets
- Access to income

It should be noted that these challenges are not necessarily unique to Cabo Delgado specifically, and similar challenges have been identified throughout Mozambique (ACTED, 2023; Eide & Kamaleri, 2009; UNFPA, 2021) and, indeed, in all worldwide humanitarian settings. Certainly in Cabo Delgado, these challenges are magnified by the conflict humanitarian setting and movement of internally displaced persons (IDPs).

Main Take-Aways from KIIs

The KIIs were particularly helpful in identifying areas in which Light for the World should consider in developing the rapid assessment tool. These include:

- In humanitarian settings such as Cabo Delgado, there is often a 'List' of persons waiting to receive assistance that can be excluding of, and difficult to access for, persons with disabilities and older persons. Attempting to by-pass 'The List' (e.g. the WFP list) to receive humanitarian assistance by offering direct information and support from the rapid assessment tool would be welcomed.
- Making referral pathways clear.
- Tapping into local leaders and 'disability champions' that are already known by OPDs.
- Emphasizing 'participant voice' rather than a top-down approach to services.
- Using mobile phones, either by the beneficiaries themselves (ideal) or by enumerators/data collectors/field staff, as mobile phone use is fairly ubiquitous.
- Locate internally displaced persons (IDPs) and community hosts.
- Greater coordination of service providers.
- Make the rapid assessment tool simple and accessible.
- **Utilize OPDs more effectively to collect data and deliver local services.**
- **Involve persons with disabilities with data collection.**

The last two emphasized points were mentioned by all of the KIIs and significantly supported by the literature.

Research Question 2

With a focus on humanitarian action, what is the current state-of-the-art in identifying and assessing persons with disabilities and older persons? To which stages of a humanitarian response are these methods and approaches relevant? Are the methods applicable in diverse humanitarian contexts?

"If people with disabilities remain invisible in data, they remain unaccounted for."
(Abualghaib, et al., 2019, p. 6)

The direct answer to this research question is:

- **Current global practices for identifying and assessing persons with disabilities are primarily centered around the Washington Group Questions (WGQs).**
- However, these were primarily designed for large scale prevalence understanding and international comparison, and not necessarily for more operational utilization.
- **All of the usages of identifying and assessing persons with disabilities beyond census-taking and population-prevalence-setting that we could find in the literature were to understand what kinds of services and interventions were *needed*, rather than connecting to already-existing services.** This extends to humanitarian settings as well.

The critical question that must be asked in identifying and assessing persons with disabilities is: *why*? There must be a purpose for such data collection, whether it be for individual identification, population data disaggregation and understanding, or the utilization of data for decision-making. It is the latter reason that we believe is the most important for Light for the World to consider in designing a rapid assessment tool.

There is significant support in the literature for the importance of the collection of disability data. Disaggregation of disability data and estimation of prevalence rates in a population are important to identify areas of exclusion and support monitoring and evaluation of efforts to eliminate those barriers (Abualghaib, et al., 2019). Much of the literature that we found and analyzed pointed to the purpose of disability data collection to design meaningful interventions *after* data collection occurred (e.g. Chemonics, 2022; Plan International, et al., 2015). However, there was little literature that we found that connected disability data collection as a connection point to *already-existing* services.

The Washington Group Questions (WGQs) are the current and most widely used disability data collection tool (Chemonics, 2022). However, there are other tools such as the World Health Organization's (WHO) Model Disability Survey (MDS) and the International Labour Organization's (ILO) Disability Module. The report from Chemonics (2022) titled *Monitoring and Evaluation Strategies for Disability Inclusion in International Development* that is included in the bibliography and attached documents file has a nice table of many tools and methodologies for measuring inclusiveness of donor funded activities and spaces, as well as tools for generating disability-disaggregated data (beginning on page 7).

However, one issue with the WGQs is that while they may capture functional limitations in various attributes, they may not necessarily capture the subjective experience of identifying as 'being disabled' (Baart, et al., 2023). In other words, the WGQs may be good for capturing large-scale disability disaggregation data but may not necessarily capture the subjective experience of the person and their specific

needs, challenges, and assets. As Baart, et al. (2023) argue, the disability data collection tool makes a difference in how a person is framed as ‘having a disability’ but should not be a replacement for supporting each individual’s needs regardless of functional scores. Other research (Boggs, et al. 2022; Schneider, et al., 2009) suggests that the WGQs work best as a first-stage population screening tool and government census-taking activity, but not necessarily in making on-the-ground service and support decisions. That being said, a meta-research analysis of non-WGQ disability assessments found that there were difficulties in data comparison, data disaggregation, and problematic disability self-reporting questions (Hillgrove, et al., 2021). In the end, the use of the WGQs need to be for a specific purpose, and not just included in data collection because it is expected. “Asking the Short Set to interpret accessibility needs prior to, for example, a workshop is cumbersome in comparison to asking a direct question on accessibility needs. The benefits of asking OPD members the Washington Group questions are not clear when a direct question would suffice” (Robinson, et al., 2021, p. 9)

Another issue with the application of the WGQs when they are used by NGOs is that there is often a disconnect between the data-gathering activity of understanding prevalence and how that data is used to inform programming and interventions (Robinson, et al., 2021). Robinson, et al. (2021) note:

Examples of use that showed clearer program benefits were as a screening tool with subsequent follow up. If the aim is to increase participation in program activities by identifying people who may otherwise be excluded, it is appropriate to use the ‘some difficulty’ rather than ‘a lot of difficulty’ cut off. While the Washington Group recommends the latter for disaggregation of data from censuses and national surveys, the Group recognizes disability is experienced on a continuum. As noted, the ‘some difficulty’ response category captures a wide range of difficulty levels, and including the ‘some difficulty’ response can minimize the risk of missing potential program participants. (p. 9)

The literature strongly supports that disability data collection be supported at every stage of decision-making and implementation by persons with disabilities and OPDs (CBM, 2015; Rohwerder, 2015). NGOs that have deployed the WGQs in their programming reported that including OPDs and persons with disabilities in data collection have significant better results in terms of data disaggregation, analysis, and program participation; although it made a difference if the WGQs were deployed strategically and with sensitivity to local context (Robinson, et al., 2021).

Considerations for Humanitarian Settings

In terms of humanitarian settings, as echoed in RQ1 above, persons with disabilities tend to be identified that have physically visible disabilities and are already known to OPDs and NGOs. A major missing population in humanitarian assistance are those that are experiencing mental illness (Miller, 2022) or otherwise have non-visible disabilities. The article by Sloman and Margaretha (2018) on using the WGQs for

disaster risk reduction (DRR) and humanitarian action in the Philippines, Indonesia, and Bangladesh is the best article we could find that is relevant to the humanitarian portion of the research question. They found that the WGQs worked well when those that are deploying the WGQs are sufficiently trained and supported, the WGQ set is bespoke to meet the specific needs of the humanitarian setting, and the WGQs are supplemented with other questions that are more specific to immediate needs and services. Arbeiter-Samariter-Bund (ASB) used the WGQs and merged them with their Information Action model in their work in humanitarian settings and DRR in South and Southeast Asia (Sloman & Margaretha, 2018). The Information Action model is the following:

1. Can everyone access the DRR information you are providing? (Information)
2. Can everyone act on the DRR information you are providing? (Action)

These questions were then followed up with:

1. Can a person act Independently (the 'I' for independently) or:
2. Is Assistance required? (the 'A' for assistance)

The Information Action model was then conceptually combined with the WGQs for utilization of humanitarian action:

1. Do you have difficulty seeing, even if wearing glasses? (Information/Action)
2. Do you have difficulty hearing, even if using a hearing aid? (Information)
3. Do you have difficulty walking or climbing steps? (Action)
4. Do you have difficulty remembering or concentrating? (Information/Action)
5. Do you have difficulty (with self-care such as) washing all over or dressing? (Action)
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood? (Information)

This was found to be effective by ASB (Sloman & Margaretha, 2018).

In a case study on disability-inclusion and humanitarian action in South Sudan, Funke (2022) had these valuable insights:

With respect to more robust and reliable data, all cluster leads in South Sudan could establish inter-cluster data management working groups to agree on certain standards for data collection, including the use of the WGQ-SS in all community engagement surveys and other questionnaires. Regular experience sharing on their application and use in the field could generate confidence among humanitarian staff and increase knowledge on the challenges of identifying persons with disabilities. In regions that are not physically accessible, humanitarian organizations should assume that at least 15% of the population has a disability. Partially this is already happening, but organizations need to make corresponding adjustments in their budgets – otherwise they will lack the financial means for reasonable accommodation, and this will effectively limit their ability to communicate and engage with persons with disabilities. Moreover, humanitarian organizations could identify key informants in inaccessible regions and train them to collect and interpret data on disability; this would enable these organizations to better deal with tight donor deadlines and travel restrictions. (p.392)

These issues of coordination, prevalence, budget effectiveness, and working with local disability partners that are raised by Funke resonate throughout the literature that has also been reflected here in this report.

Considerations for Older Persons

As has been mentioned above, there is very little literature specific to older persons as a separate consideration. In the Governance and Social Development Resource Centre (GSDRC) Topic Guide (Rohwerder, 2015), older persons are mentioned several times and included in other references in the reference list, but every mention was in combination with persons with disabilities, i.e. “persons with disabilities and older persons.” This is similar to other literature that we have found (Akerkar & Bhardwaj, 2018; Robinson, et al., 2020). Other literature refers specifically to older persons *with* disabilities (Friedrich, 2018; Help Age International, 2018). Older persons, in general, are identified in the literature as a being overlooked in humanitarian settings (Duault, et al., 2018; Karunakara, 2015). According to Duault, et al., (2018), older persons have specific challenges in humanitarian settings related to:

... physical access to care facilities and to food and clean water; triage practices by humanitarian staff that might prioritise children, mothers, and younger adults above elderly people; comorbidities; insufficient humanitarian staff expertise in the health-care needs of elderly people; insufficient supply of medications and treatments typically needed by older patients; interruption of treatment, particularly for chronic conditions; and the cost of care, among many other issues. (p. e14)

Therefore, we believe that to continue to include older persons in the overall conceptualization is appropriate, but the literature does not highlight any specific needs of older persons that would be different than persons with disabilities – and, indeed, *any person*. The point of the WGQs are to assess functionality and identify needs and challenges for anyone in a population. Older persons will be assumed to have a higher prevalence of mobility challenges but may not need other services such as education and employment.

That being said, one specific challenge for older persons in Cabo Delgado that was mentioned in our KIs was that older persons are often the primary caregivers for young children while the child’s parents were working or seeking work and assistance services (also identified by Karunakara, 2015). This presents some specific challenges in terms of ability to provide adequate childcare, particularly if the older person was experiencing mobility challenges or mental health challenges.

We recommend that the care of children by older adults be considered when designing the rapid assessment and service utilization tool for Light for the World. While most of the assessment of older adult functionality and need is covered by the WGQs, this is a specific case of identifying need and support for older adults and

there should at least be a question on the rapid assessment around this. A suggested item is the following:

[For those that identify as an older person] Do you provide primary care for a child/children? For example, caring for a grandchild while the child's parents are working or seeking employment?

If yes, do you find this care challenging to perform because of physical limitations?

If yes, what assistance or services would be most helpful in caring for that child/children?

Ethical Considerations

Through the KIIs, we learned that many IDPs and those within the humanitarian setting in Cabo Delgado were becoming somewhat weary of giving their data to others when they did not see a direct benefit to themselves as a result. This is understandable and raises the question of ethics for a rapid assessment tool. As we said above, the use of the WGQs needs to be deployed with specific purpose and utilization. In the next section, we will discuss mixed-method approaches to data collection in humanitarian settings, which needs to have a similar purpose in terms of benefiting participants and users.

As we have discussed throughout this report, it is ethically best-practice to include persons with disabilities themselves in all aspects of data collection and utilization – from design, to collection, analysis, and utilization (Plan International, 2015; Tanabe et al., 2018).

In an example of data collection methodology in humanitarian settings in Jordan, Humanity and Inclusion (2018) had this to say regarding ethics:

In order to manage expectations effectively, the research team clearly explained that participating in the study would not lead to any direct benefits, nor could the team provide diagnostic or individual case management support. At the end of the interviews, all households were provided with HI contacts to inquire about available services. Information brochures were distributed in camps.

The study team shared and discussed the research objectives and implementation plan with key stakeholders in Jordan, including with UNHCR, UNICEF, and with several NGOs and governmental entities. This took place through individual meetings and presentations delivered during sector coordination working groups. Consultations were also conducted in order to refine the questionnaire. For data collection in Azraq and Zaatari camps in particular, the team followed the Standard Operating Procedures (including assessment tool review by working group members) and obtained required approval. (p. 19)

The Humanity and Inclusion Jordan report specifically notes that they followed standard research protocols such as informed consent and right-to-withdraw. They also note in the passage above that they were clear that no direct benefits would result from their data collection towards participants. This is an important point in noting that all of the examples of assessments that we found were collecting data in order to understand the situation and then to plan programs and interventions based on the data. These examples were not a rapid assessment tool that was designed to be a direct benefit to participants in and of itself.

The passage above from the Humanity and Inclusion Jordan report also references the *Standard Operating Procedures for Coordinated Needs Assessments* (Jordan Refugee Response Inter-Sector Working Group, 2017), which is a useful document for review and adoption by Light for the World, particularly in their guidance, ethical questionnaire, and recommendations for research considerations in humanitarian settings. The full document has been included in the files attached to this report. As an example, this is the Ethical Questionnaire (p. 7):

- What information is sought from the assessment?
- What relationship does the information sought bear to programming for the refugee or host communities? What impact, if any, will it have on programming?
- How far does existing secondary data inform the programmatic design/improvement described above?
- What are the risks involved in conducting the assessment? How are these risks mitigated?
- How are age, gender and diversity incorporated into the proposed sample?

Phase	Risks (i.e. to quality of data)	Mitigating measures
Secondary data collection	<ul style="list-style-type: none"> • unrepresentative sample • non-disaggregated data (W,G,B,M) • scope of existing secondary data too narrow • methodology of existing reports was flawed • major or significant informants were not consulted • data not verified 	
Primary data collection	<ul style="list-style-type: none"> • consent may not be free and informed (especially if working with children) • participants are not fully able to refuse to participate (especially if participants are approached through service providers) • information may not be treated confidentially • assessment team does not have expertise to deal with protection or other issues arising • assessment team does not have information on referral pathways/SOPs • similar questions have already been posed and so participants' answers may be influenced 	

Another ethical factor to consider in developing a rapid assessment toolkit for persons with disabilities is the accessibility of the tool and capability of the participant. Many data collection tools use proxy respondents – such as the survey example from Bhutan further in this report – but it should not be assumed that persons with disabilities cannot answer for themselves. An exemplar and promising template for Light for the World is the Rapid Assessment of Disability (RAD) that was developed by the University of Melbourne (The Nossal Institute for Global Health & Centre for Eye Research Australia, 2015) contains important information regarding the ethical consideration of the RAD tool. In the passage below, the RAD tool discusses the rights of participation by persons with disabilities and the use of proxies. The RAD is further explained in the next section.

People with disability have the right to participate in research and should be given every opportunity to give informed consent and speak for themselves, rather than through a proxy. To facilitate this, researchers need to:

- *Provide the plain language statement in a variety of formats (e.g. Braille, large print, signing interpreters).*
- *Ensure adequate time and resources are available. Additional time may be required to ensure participants completely understand the nature of research and what they are being asked to do.*
- *Discuss with participants the possibility that their capacity to consent or to participate in the research may vary or be lost, and the participant's wishes about what should happen in these circumstances.*

Consent to participate in research by someone with a cognitive impairment, an intellectual disability or a psycho-social disability should be sought from that person if they have the capacity to do so. Where the impairment is episodic or temporary, attempts should be made to obtain consent at a time when the impairment least interferes with the person's capacity to give consent. In some cases, it may be difficult to determine a person's capacity to give consent, and it may be necessary to consult with a person's guardian or gain consent from a person authorised by law to give consent. If consent is given by a guardian, or a proxy will be responding on behalf of a participant, researchers should still explain to the participant about the nature of research and what participation involves, and ensure they are happy for their guardian to complete the questionnaire on their behalf.

In the RAD questionnaire, participants are given the opportunity to give consent to complete the questionnaire on their own, with support from someone, or to give consent for a parent/guardian to respond on their behalf. (The Nossal Institute for Global Health & Centre for Eye Research Australia, 2015, p. 39)

Promising Example of Rapid Assessment of Disability

The University of Melbourne (The Nossal Institute for Global Health & Centre for Eye Research Australia, 2015) developed the Rapid Assessment of Disability (RAD) toolkit in order to:

- measure the prevalence of disability within a target population;
- understand the impact of disability on well-being and access to services, including barriers to access. This information can assist program designers to understand the priorities of people with disability in order to inform the design of inclusive development projects;
- contribute to the evaluation of disability inclusive development projects.

The intention was for NGOs, donor agencies, and governmental agencies to deploy the RAD and to disaggregate the data by age, gender, socio-economic status, education and occupation. The RAD was piloted and validated in both Bangladesh and Fiji.

The structure of the RAD is a household survey questionnaire and an individual questionnaire and administered by a field worker. Thus, there is a need for field staff that need to be maintained on the ground and is cost and labor-intensive – which is a drawback of the RAD. There are three sections to the RAD: a demographics section, a self-assessment of functioning section, a wellbeing section, and a section on access to the community. The contents of Section Two of the RAD were informed by the Washington Group, as well as the World Health Organization Disability Assessment Schedule II (WHODAS II), the Activity Limitation Scale and Participation Restriction Scale (ALS/PRS), the Kessler Psychological Distress Scale (K6), and the ICF checklist [15-19]. Section Three contents were informed by the World Health Organization Quality of Life-BREF (WHOQoL-BREF) with the remaining items sourced from the ALS/PRS, the Participation Scale, WCG and WHODAS [15-17, 20, 21].

In terms of linking data to specific assistance and services, the University of Melbourne (2015) had this helpful description:

The RAD questionnaires include some sector-specific items in Section 4 such as education, health and water, sanitation and hygiene (WASH). Sector-specific programs however, might require more detailed information to fulfil planning, monitoring and evaluation needs. According a project's purpose, there could be other items and methods required to gather information for planning. Further information could be collected using sector-specific surveys or through qualitative techniques such as in-depth interviews and focus group discussions. Information collected using sector-specific surveys in combination with the RAD questionnaires, could allow programs to disaggregate data by disability to help monitor inclusion of people with disability and the program's impact on their lives. (p. 40)

The full questionnaire, background, and justification for the RAD are included in the bibliography information and attached files to this report. We believe that there is potentially a lot that can be learned from this example.

Research Question 3

What is the current state-of-the-art on using mixed-methods tools and approaches for disability-inclusive planning, programming, and/or policy?

To answer this research question directly:

- The best mixed-method tools and approaches are participatory processes that include persons with disabilities in every stage of data design, collection, analysis, and application.
- The literature supports and champions the use of qualitative data to provide richer and more robust data that can better capture the subjective experience and service needs of individuals.
- Qualitative and mixed-method data collection methods often require use of field staff and on-the-ground data collectors which can be resource-intensive. Therefore, using technology such as smart phones and beneficiary-driven tools could be an innovative and cost-effective approach.
- However, most of the literature points to this kind of mixed-method gathering as an entry point to design new services and interventions, and not necessarily connecting participants with existing services (e.g. Plan International, 2021; Robinson et al., 2021; Sloman & Margaretha, 2018; Tanabe et al., 2018).

Mixed-method tools and approaches are relatively common in disability data collection by NGOs, particularly when the data collection has the purpose of not only understanding population prevalence data, but also in planning disability-inclusive programming, interventions, and assistance. The data collection by IOM (2022), with assistance from FAMOD in Cabo Delgado, for example, has rich qualitative data via focus group discussions that was thematically analyzed and produced key challenges for persons with disabilities in the region. A study from Somalia on disability data collection in humanitarian settings suggests that qualitative tools make the data much more robust and easier for utilization:

Specific considerations should be placed on how assessments are conducted, including the training of enumerators and who those enumerators are, as well as the basic operating assumption that most data are collected at the household level. For example, if we take the food security sector, planning and response is driven through large-scale needs assessments or surveys. Ideally, this is accompanied by qualitative tools such as community consultations which allow greater understanding to inform targeting decisions, prioritization and response. (Young, 2023, p. 407–408)

Humanity and Inclusion conducted a comprehensive assessment of disability of Syrian refugees in Jordan and Lebanon using a mixed-method approach of both a quantitative survey (with WGQs) and a qualitative component using focus groups discussions (FGDs) and KIs. "Semi-structured interview guides were used for both

KIs and FGDs. FGDs applied child-friendly methods using animal toys, ‘smileys’ and picture drawings to encourage children to express their views” (Humanity & Inclusion, 2018, p. 18). While this study produced robust and comprehensive data on the situation of persons with disabilities in humanitarian settings in Jordan and Lebanon, the purpose of data gathering was more for understanding the ‘next steps’ in terms of service delivery and interventions. This is a common refrain in the literature (i.e. Kikuni & Mudage, 2023). However, we would recommend that Annexes in the Humanity and Inclusion (2018, pp. 84–95) report as it gives the entire data collection process from data collection tools to analysis.

Within a rapid assessment tool, qualitative data can be both time-intensive and resource-intensive, but much more effective overall for program delivery and intervention design (O’Reilly et al., 2021). Rapid assessment tools such as the RAD (The Nossal Institute for Global Health & Centre for Eye Research Australia, 2015), cited in the previous section, included open-ended, qualitative responses. Other exemplars of mixed-method approaches such as from Jordan (Humanity & Inclusion, 2018) and the Information Action model (Sloman & Margaretha, 2018) can be done or modified to be performed within a relatively short period of time. However, these examples of good practice all represent tools that are deployed via field staff that involve use of resources. While we could not find any specific example of mixed-method rapid assessment that did not involve field staff, there are examples of using technology such as GIS-enabled smart phone apps to collect data, such as in the Bhutan example below and also with tools such as Kobo Toolbox. These can potentially be adapted for use by beneficiaries themselves, as there is already a precedent in Cabo Delgado for the use of a humanitarian service hotline by the UN cluster.

As noted above, the WGQs are limited in terms of their use beyond prevalence baseline census-taking. Robinson, et al. (2021), in a convincing meta-study of the use of the WGQs by NGOs, found that the WGQs alone were not effective in supporting NGO programming. This suggests that the WGQs need to be part of a more comprehensive, mixed-method, approach to not only understanding the situation of persons with disabilities in humanitarian settings, but also in seeking user- or beneficiary-informed solutions to identified challenges rather than a ‘tick-box’ exercise (O’Reilly, et al., 2021).

One potentially promising practice that we found in the literature was **Participatory Learning and Action (PLA)** (Plan International, et al., 2015). This data collection practice values and preferences the voice of a person with a disability in identifying barriers and enablers in their community and subjective experience. This method involves collecting stories of history, experience, and opinion. We would also argue that participatory accessibility audits can also be used in a more action-oriented or operational way to both empower persons with disabilities to share their lived-

experiences while at the same time understanding pathways to services or better ways to provide access to humanitarian services.

In a project of sexual and reproductive health (SRH) for persons with disabilities, the Women's Refugee Commission (WRC) conducted participatory action research in refugee camp settings in Kenya, Uganda, and Nepal (Tanabe, et al., 2018). The WRC recruited local community leaders and persons with disabilities as data collectors, and these local data collectors received a 4-day training for data collection. Participants had three opportunities to learn about activities, ask questions, and decide if they wished to be a part of the data collection process. The data collection itself was action-oriented as involved participants engaging in SRH activities such as body mapping, timeline life mapping, safety mapping, scenario discussion, and interviews. Some of these activities could potentially be useful in thinking about Light for the World data collection in Cabo Delgado, particularly mapping activities and scenario discussions that involve participants thinking through access to services and brainstorming solutions to service accessibility.

Case Study from a Project in Bhutan

From 2018–2022, Matthew Schuelka was primary investigator and project lead on a project titled, "Understanding, Developing, and Supporting Meaningful Work for Youth with Disabilities in Bhutan: Networks, Communities, and Transitions," funded by the Foreign, Commonwealth, and Development Office (FCDO) in the United Kingdom and managed by the University of Minnesota (USA), Royal Thimphu College (Bhutan), and the University of Birmingham (UK). *The Comprehensive Survey of Transition and Employment of Youth with Disabilities in Bhutan* was conducted in 2019 and 2020 (Schuelka, et al., 2022). The survey was Phase One of the project and included 216 youth with disabilities (average age: 23) across 17 out of 20 *dzongkhags* [districts] in Bhutan. Fieldwork surveys and interviews were conducted in person, using Geographic Information Systems [GIS]-enabled technology, but it also integrated the WQs as baseline data. The survey was only part of the Phase One data gathering process, as we also used GIS data-gathering tools to interview participants and document their lived-experiences,¹ and conducted focus groups and KIs through a political economy assessment lens.

While the objectives in Phase One were centered around situational analysis and understanding the barriers and enablers of persons with disabilities in Bhutan, one purpose of collecting these data was to directly feed into our Phase Two interventions. In Phase Two, we used what we learned in Phase One to tailor our employment skills and entrepreneurship training topics to the needs of our participations. We also launched an Employment Assessment Toolkit (Lynch, et al.,

¹ Examples of the Bhutanese 'StoryMaps' can be found at: <http://www.mappingdisabilitybhutan.com>

2023), a Microgrant entrepreneurship scheme (Schuelka & Johnstone, 2023), and hired Community Inclusion Coordinators (Johnstone & Schuelka, 2022) to interface and facilitate between persons with disabilities, NGOs, the Bhutanese OPD (there is only one), government, and private employers.

Through our mixed-method data collection in Phase One, particularly in using GIS-mapping tools, we were able to identify participants for the above trainings and schemes, continue to follow-up with participants and track their progress (particularly as they moved around), and work with local district governments and NGOs to make persons with disabilities known to them and to facilitate support pathways for persons with disabilities. Through that facilitation, we linked persons with disabilities to existing services that were offered, in addition to our Phase Two bespoke interventions.

The Comprehensive Survey of Transition and Employment of Youth with Disabilities in Bhutan is included in the additional files submitted with this report. The survey itself was created, disseminated, and analyzed through the ArcGIS smartphone and tablet app, Survey123. While this project deployed field workers to collect data, the app could have been accessed by anyone in Bhutan. For Education has also piloted a community engagement toolkit that is directly used by beneficiaries (youth with disabilities) in Singapore and we are also currently developing a similar app in Malaysia.

Conclusion: Application of Bhutan Case to Cabo Delgado, Lessons Learned from the Literature

In terms of lessons learned from the Bhutan study that can be applied to Light for the World's work in Cabo Delgado, while the context is not exactly similar in the sense that Cabo Delgado is a humanitarian setting and Bhutan is a low-and-middle-income country, we believe that a similar approach to data collection and utilization could be helpful. By using GIS-enabled data collection tools, we were able to better visualize and literally map participants and access to basic needs and services. Similarly effective mapping has been done by Three Stones International in locating centers of literacy in Rwanda.² Although a rapid assessment tool would certainly be most efficient and effective if it could both identify and assess as well as provide utilization and pathways to humanitarian services at the same time, Light for the World may want to consider two phases to the data collection process in terms of first gathering information of participants – particularly through already-existing FAMOD/OPD networks – and locations of existing service provision, and then mapping out pathways to those services both literally and conceptually. Using GIS-

² Presentation at the Comparative and International Education Society Annual Meeting, Washington, DC, 2023. Project document publications pending.

enabled data gathering tools can also be dynamic and useful for a mobile and itinerant population in Cabo Delgado.

Overall, the literature identifies that the WQOs are fairly ubiquitous in data collection both overall, as well as in humanitarian settings. However, these should be used cautiously, with clear purpose, and with full understanding of their limitations in what they can and cannot do. A good example such as the RAD (The Nossal Institute for Global Health & Centre for Eye Research Australia, 2015), in the box above, shows that the WQOs can be integrated into a more comprehensive data collection tool that has a clear objective of both situational analysis as well as application. Using mixed-method approaches – particularly participatory approaches – has much greater effect and utility. However, there is no literature that we could find that links the data collection phase directly to already-existing services as generally data collection is the first activity in a project cycle. Rather, good examples of mixed-method approaches used data to inform future programming and service-offerings.

One theme that is very clear from the literature, that cannot be stressed enough, is that persons with disabilities and OPDs *must* be participatory stakeholders as data collectors, key informants, community inclusion facilitators, and service-users. Several participatory methods were highlighted above, particularly from Plan International (2015). Another exemplary project was given above from ASB (Sloman & Margaretha, 2018) in their conceptual framework of Information Action to provide action and application stemming from the WQOs.

Nearly all of the data collection and project examples from literature involved ground staff and field teams to facilitate data collection. While many times these field teams were persons with disabilities and OPDs, as mentioned above, these still involved an intensive use of resources and commitment from an organization. For example, enumerators needed to be trained to conduct fieldwork at the very least. We could not find any examples from the literature of remoted-based data collection via smart phone, tablet, or other electronic means. This does not necessarily mean that these would not be effective practices, but it does mean that Light for the World will have to be the innovators here. As KIs shared, the use of hand phones is already wide-spread in Cabo Delgado, so an app-based or phone-based data collection system could be quite effective, and some basic coding could connect data input by the user and then receiving vital service information and pathway referrals back. This could also solve that issue of ‘survey fatigue’ in Cabo Delgado where participants in surveys do not feel that they receive anything for their time.

The literature also had little to say about specific issues faced by older persons, separate from persons with disabilities. While there is much overlap in terms of

functional challenges between older persons and persons with disabilities, there is at least one unique issue in terms of older persons providing childcare. A suggested survey question was given above to attempt to disaggregate challenges faced by older persons specifically. Otherwise, a survey will also be able to disaggregate data by collecting age information and proceeding with the WGQs and other survey items shared by all participants.

In conclusion, this literature review recommends that Light for the World proceed with a mixed-method data collection process that incorporates the WGQs, but with purpose and intent. The emphasis of 'good practice' from the literature in regard to similar projects is on the importance of *process* rather than results. This includes the inclusion of the data collection process itself. Light for the World will have to be an innovative leader in designing a rapid assessment tool that have immediate utility for the user, rather than a formative evaluation tool used to design future programming and services. An iterative design process for such an applied rapid assessment tool with user and stakeholder input is a great place to begin.

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