Seeing the unseen

Nadir Abu-Samra Spencer and **Clodoaldo Castiano** look at a community-driven, mixed-methods tool designed to assess barriers and enablers for persons with disabilities and older individuals in humanitarian settings

The World Health Organization estimates that one in six individuals lives with a disability. Applying the UN Office for the Co-ordination of Humanitarian Affairs' data on populations affected by crises worldwide (over 300 million) suggests that approximately 64 million persons with disabilities are affected.

Disproportionately affected and exposed, persons with disabilities and older individuals are systematically under-represented during needs assessments and response planning. Humanitarian services may also be inaccessible because of the barriers these groups face, increasing risk and vulnerability.

It is not a surprise, therefore, that persons with disabilities are up to four times as likely to die during crises. However, the key to understanding the problem and acting on it is to understand disability as the interaction between individuals with impairments and the social, legal, political, and environmental barriers they face. This rights-based disability model ensures that data can be collected and analysed to identify and remove existing barriers to accessing humanitarian assistance.

In stark contrast to charitable and medical models, the human rights-based approach also places people with disabilities at the centre of humanitarian action, recognising their capacity to contribute to preparedness, response, and recovery. It also calls for their meaningful participation in decision-making, in line with the principle of 'nothing about us without us'. In addition to data collection, the identification and removal of barriers, and meaningful participation, empowerment and capacity development of persons with disabilities are also must-dos for disability-inclusive humanitarian action.

From an operational perspective, achieving disability-inclusive humanitarian action requires both specifically supporting and systematically including persons with disabilities. This twin-track approach relies on the complementarity of mainstreaming and targeted intervention, for which reliable data is crucial.

Members of Famod co-ordinated and conducted the survey of over 2,500 people in the IDP camps of Metuge and in Pemba, the state capital of Cabo Delgado

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Designing and implementing disability-inclusive humanitarian programmes requires a few elements. For starters, it includes estimates on the number and distribution of persons with disabilities within the affected population, and understanding how crises affect their mortality, nutrition, livelihoods, health, and protection. Then, it involves capturing their views and priorities, as well as monitoring access to services and assistance to identify barriers. Last, it comprises strengthening the evidence base for advocacy, awareness-raising, and capacity-building efforts.

However, collecting reliable data in emergencies poses significant challenges. Many humanitarian programmes struggle to identify persons with disabilities within affected communities and to disaggregate data by disability, age, and gender. Other factors, such as stigma and discrimination, further hinder open disclosure and accurate reporting.

Moreover, persons with disabilities are a diverse group – differing by type of impairment, gender, age, ethnicity, and other aspects. An intersectional lens is, therefore, also needed from data collection to analysis and use to prevent multiple and compounding forms of exclusion and discrimination.

Collecting both quantitative and qualitative data then becomes indispensable. Quantitative data help to map prevalence and access, while qualitative insights reveal lived experiences, barriers, and enablers. Together, they provide a comprehensive evidence base for inclusive, equitable, and accountable humanitarian action.

The solution to these issues then had to be created: Built with communities, grounded in rights, and designed for real-world humanitarian use. The result was Survey for Inclusive Rapid Assessment (SIRA), a mixed-methods data collection tool designed to assess disability prevalence and the barriers and enablers individuals face in accessing humanitarian assistance.

Ground zero

SIRA grew out of work undertaken by Light for the World International, a global disability and development organisation headquartered in Vienna, Austria, undertaken in Mozambique. The country faces recurring climate shocks, such as cyclones and droughts, as well as armed conflict in Cabo Delgado, the northernmost province. In this context, reliable data on persons with disabilities was urgently needed to make humanitarian assistance more inclusive, yet in 2023, not even accurate estimates of disability prevalence was available for this intervention area.

During this time, along with Mozambique's national umbrella organisation of persons with disabilities (OPD), Forum das Associações Moçambicanas de Pessoas com Deficiência (Famod), Light for the World International co-designed, developed, and tested a novel open-source data tool for assessing the barriers and enablers that persons with disabilities and older people face in accessing humanitarian assistance.

While rooted in Cabo Delgado, the co-creation process quickly acquired both national and international

Reviews after the surveys revealed the changes in community perception from witnessing persons with disabilities collecting data and running the survey

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Accessible technology and reasonable accommodation enabled enumerators with disabilities to run the digital questionnaires

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dimensions. It brought together persons with disabilities from affected communities, OPD members, disability inclusion facilitators (DIFs), staff from national and international NGOs and UN agencies, and academics. In essence, the innovation process involved collaboration both with persons with disabilities and humanitarian actors. The team developed a theory of change for the innovation through role-plays, participatory workshops, key informant interviews, field visits, and desk research.

Recognising the operational diversity of humanitarian actors, the tool was designed to be simple, flexible, and modular, enabling straightforward adaptation to specific humanitarian programmatic areas – such as water, sanitation and hygiene (WASH) or sexual and reproductive health and rights (SRHR) – as well as to broader, multi-sectoral assessments spanning humanitarian assistance and livelihood opportunities. To ensure both global relevance and methodological rigour, the design drew on international best practices and established tools, most notably the Washington Group Questions on Disability and the Child Functioning Module; the IOM Displacement Tracking Matrix Field Companion for Disability Inclusion; and open-source and open-data principles.

Finally, to capture both disability prevalence and the barriers persons with disabilities and older individuals face in accessing humanitarian assistance, co-creation emphasised the importance of understanding the lived experience of disability and the non-linear nature of inclusion and exclusion. As a result, the data collection tool was designed as a mixed-methods instrument, combining both quantitative and qualitative approaches to produce a comprehensive and actionable evidence base.

A key element of the innovation's theory of change focused on strengthening OPD-led advocacy through data and process ownership. With the help of accessible technology, simple questionnaires, focused training, and guidance from international NGO experts, the goal was to enable Famod to take an active role in humanitarian data work, going from just collecting data to analysing it and using it for advocacy at the local, national, and international levels.

At the local level, the process linked individual referrals to humanitarian services with systemic advocacy, enabling Famod to engage directly with service providers to improve accessibility and address identified barriers. At the national level, data and evidence equipped OPDs to advocate with duty-bearers, including government, on a policy level. At the international level, inclusive data and processes served as a platform for Famod to partner with humanitarian actors and promoted more inclusive and accountable humanitarian action.

Ultimately, the co-creation process resulted in several mutually reinforcing objectives: to establish an inclusive data collection process, to inform and improve humanitarian programming, and to strengthen advocacy. These objectives are supported by the data collection tool and its associated data collection process, contributing to enhanced access to humanitarian assistance for people with disabilities and older persons.

Tools that listen

SIRA is entirely open-source; it is centred on the Washington Group Questions and the Child Functioning Module and complemented by qualitative and quantitative questions. Importantly, Washington Group questions covering psychosocial functional domains (anxiety, depression, and fatigue), as well as pain, were also included. It combines household and individual questionnaires and captures additional spatial and socio-demographic information, such as household size and displacement status.

The tool was designed with accessibility in mind, featuring screen-reader compatibility and simple language. Non-conventional formats, such as pictorial questions, were prototyped in the field but not retained, as field research revealed practical limitations. Moreover, all accessibility features in it were tested both internally by Famod and in the field. Questions, available in English and Portuguese, were also translated into Makhua and Maconde, the two main local languages in the East of Cabo Delgado.

To facilitate referrals, existing humanitarian services and organisations were mapped using lists maintained by the

Surveys conducted by Famod in Cabo Delgado in 2024 with SIRA

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humanitarian cluster sector leads. During the prototyping phase, no efforts were made to train or advise these organisations on disability inclusion, as this would have required developing specific training materials and training Famod staff, which was beyond the project's timeframe. Currently, these training materials are under development.

In the first half of 2024, around 20 Famod staff conducted surveys with nearly 2,500 individuals in Pemba, the capital of Cabo Delgado, and in internally displaced persons (IDP) camps in Metuge district. Using cluster randomised sampling, the survey included people with and without disabilities.

Preliminary findings showed that nearly 25 per cent of respondents had a disability when the Washington Group questions covering psychosocial functional domains related to mental health were included. This figure, while likely a lower bound, is significantly higher than the global average of 16 per cent, suggesting that disability prevalence in humanitarian settings may be substantially underestimated. These findings highlighted the importance of including mental health in disability prevalence assessments to inform disability-inclusive humanitarian action.

Among the approximately 500 respondents aged 50 and above, 20 per cent reported experiencing pain most days or every day, while 40 per cent experienced severe pain. Combined, these results indicated that four in 10 older persons surveyed faced debilitating pain. Given that the harsh conditions of crises can accelerate ageing, a lower age threshold of 50 years was applied. Using the more conventional cut-off of 60 years yields even higher rates of disability and related impairments, particularly those linked to pain.

The survey examined barriers across distributions, services, SRHR, livelihood opportunities, and fear – the latter also serving as a proxy for assessing gender-based violence (GBV). Two main categories of barriers emerged: those affecting the general population or specific geographic areas, and those unique to persons with disabilities. Cross-cutting barriers included difficulties in accessing food, reflecting the reality that over 1.6 million individuals in northern Mozambique are food insecure due to conflict and climate shocks. Additional widespread barriers are related to accessing health services in rural IDP camps and accessing clean, safe drinking water in urban areas.

Mobility, transportation, and communication were the primary barriers specific to persons with disabilities. Respondents reported that: services were often located far away and inaccessible by available transport; some services were provided in locations not sensitive to gender; and individuals feared accidents and injury when leaving home to access services, and in some instances even harassment, attacks or arrest. In terms of communication, persons with disabilities noted that service provider staff were often unable or unwilling to communicate effectively with them or their families; and information materials were not accessible or adapted to their needs.

Identifying both cross-cutting barriers and those specific to persons with disabilities supports a twin-track approach: applying disability mainstreaming to address general barriers, while implementing targeted interventions to remove those directly affecting persons with disabilities. For example, respondents highlighted accessible transportation and accessible information as key enablers for improving access to humanitarian assistance.

Notably, the majority of Famod staff involved in data collection were themselves persons with disabilities. The screen-reader compatibility of SIRA allowed enumerators with visual impairments to independently administer surveys, while those with hearing impairments worked in tandem with OPD colleagues proficient in sign language.

During after-action reviews, surveyors with disabilities described the experience as empowering, emphasising the value of contributing actively to humanitarian data collection. Moreover, Famod members observed a positive shift in community attitudes, as enumerators with disabilities served as visible role models, challenging stigma and reshaping perceptions of disability within surveyed communities.

The findings from data collection in Cabo Delgado were jointly analysed and subsequently used to inform advocacy at national and international levels, as well as to guide humanitarian programming in Mozambique and Burkina Faso. While Famod's experience demonstrates the full potential of such collaboration, inclusive data collection remains an urgent global priority. Data-driven interventions can, and should be, adapted to each context. CRJ

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