

# Addressing the data challenge

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## **The humanitarian relief community needs to collect disability-specific data through rapid needs assessments, registration processes, accessing local knowledge and disability monitoring.**

Current literature suggests that data on disabilities among refugee and IDP communities are often uncollected or unknown by the larger NGOs and UN agencies that are providing the bulk of relief services.<sup>1</sup> Standard procedures such as rapid assessments and registration processes often do not include collection of information specific to the circumstances, needs and presence of refugees and IDPs with disabilities. In cases of armed conflict or natural calamity, this 'invisibility' can be fatal.<sup>2</sup>

The 2008 Women's Refugee Commission's report on *Disabilities*

*among Refugees and Conflict-Affected Populations*<sup>3</sup> noted that identifying and collecting data on the number of persons with disabilities and the types and causes of disability have proven to be one of the greatest data challenges in the context of displacement. Addressing the specific needs of persons with disabilities in an emergency context requires that agencies have appropriate tools and training to recognise and record various types of disabilities. While the Sphere Project Handbook recognises persons with disabilities as falling within their 'vulnerable groups' category – people who should be

considered in all facets of service provision, along with the elderly, children and women – the Handbook does not provide minimum standards and requirements specific to these 'vulnerable groups'. Due to the diversity of disability, minimum standards of service are needed to guide agencies in qualifying and quantifying their response for refugees and IDPs with disabilities in order to fulfil their most basic rights to protection, health and dignity.

### **Data collection**

Data collection processes for emergency interventions and recovery programmes must include:

- disability-specific rapid needs assessments

- registration processes that are inclusive of persons with disabilities
- information gathering from local NGOs and community leaders, and from national/local health and/or surveillance systems
- implementation of disability-monitoring mechanisms.

One of the greatest challenges to data collection for this sector of a displaced population is overcoming the misconception that persons with disabilities require such specific and complex services that agencies should only focus on their needs once the emergency phase is over.

This notion deflects attention from the urgency of collecting such data during the standard data collection processes. Consequently, the data collected during the emergency phase and used to develop the most critical survival services are devoid of any disability-specific information. This inadvertent negligence disregards the survival and protection needs of refugees and IDPs with disabilities and their carers. Literature and case-studies alike note the lack of standardised disability-specific data collection tools and monitoring mechanisms.

The development of a disability-specific rapid assessment tool is essential in order to ensure inclusive emergency interventions. The diversity of disability demands a reference guide for those who are conducting assessments in order to increase accuracy in recording the category and severity of disabilities and to ensure that the assessment accurately measures the needs of individuals with disabilities. Additionally, a set of definitions and indicators accepted by all NGOs and UN agencies would allow for more efficient coordination, information sharing, evaluation, comparison and analysis across data sources and over time.<sup>4</sup> Training for data collectors or interviewers to detect and ask about disability is essential.

The assessment tool should enable data collectors to record:

- all categories of disability (physical, mental, sensory) and

all manifestations of disability within each category

- category of the disability
- singular, double or multiple disabilities
- criteria for identifying a disability
- the severity of (each identified) disability
- age and gender of person with disability
- number of persons with disabilities in a single 'household'
- onset of disability (at birth, after birth and prior to displacement, as a result of war/disaster, result of migration) and any necessary anecdotal information
- specific needs (transportation, assistive device, food ration assistance, water supply assistance, access to universal design latrine, accessible shelter, access to medications, access to specialised medical care, etc)
- carer situation (none/temporary/permanent)

The assessment tool will need to include a reference section with definitions of all categories and types of disabilities and severity criteria to ensure high quality and consistent data collection across humanitarian organisations.

One-off and ongoing refugee and IDP registration processes are important operational procedures that must seek to capture the presence of persons with disabilities within the displaced community. In cases where stigma, discrimination or lack of mobility result in making persons with disabilities a 'difficult-to-reach population', agencies will need to partner with community leaders, local NGOs and international NGOs with long-term presence in order to facilitate registration processes and help emergency responders to identify and register persons with disabilities. The registration process will not only provide a rough estimate of the number of those displaced with disabilities but will also enhance

their visibility and, most importantly, will directly connect refugees and IDPs with disabilities to essential services (including food ration cards, immunisation campaigns, protection initiatives, psychosocial first-aid programmes, etc). It is also important to ensure that people who become disabled over the course of displacement receive the information and services necessary to sustain their lives and livelihoods.

As mentioned, gathering information from local NGOs, local leaders and identified community members who care for persons with disabilities is important if agencies are to understand how it is to be a person with a disability in a particular society and the type of care, opportunities and protection – or lack thereof – that exist there. In situations where persons with disabilities – or persons with particular types of disabilities – are harder to reach, engaging with local leaders and organisations will be even more necessary. Their specialised institutional knowledge, resources and deeper understanding of the needs of persons with disabilities prior to displacement, as well as information on the types and prevalence of disabilities, will be of great importance in planning and implementing interventions and services. International agencies should support these local organisations and avoid poaching staff or creating parallel services. Instead, establishing partnerships and providing assistance will improve local capacity in an emergency context, improve existing services and create a more sustainable and strengthened support system for persons with disabilities.

Statistics on disabilities from the national and local health system or surveillance systems are another source of data. While the presence and/or capacity of these systems will vary greatly, they can be useful for data collection and for understanding the level of recognition of persons with disabilities within local and national government systems. Due to the impermanence of 'ability' in forced migration contexts, it is essential to establish a coordinated system that systematically collects

disability-specific data over the course of displacement. Disability monitoring mechanisms, such as disability surveillance, is a key data collection method that should be developed, implemented and charged with the duties of ongoing and systematic collection, analysis and interpretation of disability-related data. This information could be used to inform humanitarian actors on a way forward for effective disability mainstreaming, implementation and evaluation.<sup>5</sup>

### Conclusion

While the Women's Refugee Commission, World Vision and other NGOs, as well as researchers, have more recently begun to map and mainstream the needs of refugees and IDPs with disabilities, organisations such as Handicap International and HelpAge International have long worked in this environment, providing specialised care and building up a wealth of institutional knowledge, capacity and data collection tools. Their expertise should be tapped to improve humanitarian data collection, planning and programme implementation. More importantly, agencies need to take responsibility for including refugees and IDPs with disabilities in rapid needs assessments and registration processes, accessing local knowledge and initiating disability monitoring mechanisms so that they can begin to design emergency interventions and recovery programmes with inclusion in mind.

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2. Stocking, B (2003) Preface in S E A Harris, *Disability, Equality and Human Rights: A Training Manual for Development and Humanitarian Organisations* (p. viii). Oxford: Oxfam GB.

3. [http://www.womensrefugeecommission.org/docs/disab\\_full\\_report.pdf](http://www.womensrefugeecommission.org/docs/disab_full_report.pdf)

4. Gerben Dejong. Spring 2008 Forum: Dealing with disability. <http://www.issues.org/24.3/forum.html>

5. Center for Disease Control. Retrieved Jan 2010, from: <http://www.cdc.gov/ncphi/diss/nndss/phs/overview.htm>