



9. Collect data

Tariku, who has bilateral clubfoot, and his family during a visit from CBM partner Cheshire Services Ethiopia. ©CBM

Data and information are key, because what is documented and measured is ultimately what is devoted attention. Data generation is a core component of community development as part of needs assessments or monitoring, to understand what is needed on the ground and/or to evaluate whether interventions are working and having impact to then make the necessary adjustments. As community development practitioners, you are likely to already be generating information, for example on customs and culture, livelihoods, poverty levels and inequality and how all of these interact with and impact persons with disabilities and their families. Much of this information is instrumental in the design of contextually relevant and resilient projects. We will speak about resilience in depth in action point 11.

Data may already be in place, and in other circumstances, it may still need to be collected and analysed. The need for more (and better quality) data on disability cannot be emphasised enough. This is because it means stronger advocacy, it provides a more solid basis for planning and ensuring actions are in place, and is an effective tool in holding actors and governments to account.

The issue of data and information is particularly important in the case of disability and DIDRR, because data that is formally collected (e.g. in risk assessments or capacity assessments) is often not disaggregated by disability, while that which is collected (e.g. in censuses or social protection or departmental registers) is often insufficient in quantity and quality. Data is also frequently collected in dominant languages, which excludes information on multiple populations such as indigenous peoples. The result is that persons with disabilities are underestimated and consequently excluded from or marginalised in DRR, not least because lack of information weakens advocacy. It also feeds into the exclusions in community development work, by rendering invisible how disasters interact with and impact persons with disabilities and development efforts. Disasters and DIDRR are therefore relegated to the back with no provisions made in these times when sudden stresses and shocks are becoming more frequent, hard to ignore, and which can destroy development efforts quickly.

Governments and organisations, including those working in community development, need reliable data to account for persons with disabilities before, during and after disasters, which is therefore a core component of mainstreaming. The need for country relevant data, in particular, is extremely important, because politicians can try and discredit global statistics as irrelevant to the national context.

Data and information that is related to disasters is broad ranging and it may be helpful to include this as a critical component in community development whenever possible. Obviously, it is difficult if not impossible to generate data on everything, not least because information on a number of dimensions may well be unavailable, too costly and/or time-consuming to obtain. It is also not within your capacity or responsibility to try and collect most of it! What we are after here is data that can help not only with the mainstreaming of disability in DRR, but that can also alert stakeholders working in social and community development, including disability-specific sectors, to seriously mainstream DRR in their portfolio as a matter of urgency.

So, what information and data are needed? It is hard to have a comprehensive list, not least because every context is different, and hazards have different repercussions. But here are some pointers (see the box below).

WHAT DATA AND INFORMATION ARE NEEDED?

The number of persons with disabilities living in the area of intervention.

The numbers that develop secondary impairments through injuries or who perish.

The number of persons with disabilities left out of DRR programming.

Gather and impart key information, for example the proportion of national or regional DRR budget allocated to disability.

Proportion of social development and other budgets devoted to those living in precarious conditions.

Data from damage impact assessments, and where possible the multiple barriers confronted by persons with disabilities in disasters (social, environmental, economic, political, infrastructural etc.) and how these are interconnected.

Information on financial protection schemes, distribution mechanisms in emergencies, how accessible these are, and if and how they are taking disability into account.

The economic costs of excluding persons with disabilities from DRR.

Number of evacuation routes that are accessible.

Transportation and other infrastructure critical in evacuation.

DRR systems in place and where responsibilities for management lie.

Early warning systems, whether they are accessible, and the areas they reach or exclude.

Different communication strategies for warning of impending hazards and their accessibility and effectiveness.

Data on rescue intervention procedures, resources, technologies and tools, and contact information of key providers.

Environmental changes and possible hazards.

But how do we go about collecting such data and what can you do?

Step 1: **Advocate** for inclusion of disability in formal demographic, social, economic, technical and other data generating exercises such as:

- censuses and household surveys, including those on environmental issues and disasters, and to call for a budget for this
- rapid needs assessments conducted immediately after a disaster to provide quick information on access and act on gaps in intervention and planning.

Step 2: **Collect your own information** by meeting and talking with people, whether through informal discussions or focus groups, inferring from existing data and/or equipping others to generate information.

Here are some good practices blending these two steps. Remember that data generation does not always need to be complex or technical, and both formal and informal means are legitimate. Much information can in fact be gathered during your regular field trips. The box below provides some useful tips:

LET'S GATHER SOME INFORMATION

Take notes on your field trips e.g. on reduction in crop output, access to water etc.

Include any risk and crisis information as part of your regular monitoring and data gathering.

Provide technical support to government, for example by promoting the Washington Group Set on Functioning questions¹⁴ which can be used in censuses to gather information about limitations in basic activity and functioning.

Strengthen and train OPDs in basic research methods and how to use indicators to monitor and document the inclusion of persons with disabilities in DRR.

Work with OPDs and community members to scan the context to see what exists, for example what early warning systems and preparedness measures are in place and how they work.

Gather information about who has power and who takes key decisions as part of a mapping exercise.

Extract data from censuses or information gathered by ministries, departments and other entities, in particular statistical information looking at different areas, for example disasters, health, education etc. and then collate, infer and/or use indicators to produce your own statistics. Though not precise, these can be used with politicians to make a case for disability inclusion in DRR.



¹⁴ Washington Group on Disability Statistics. [The Washington Group Short Set on Functioning \(WG-SS\)](#).

LET'S GATHER SOME INFORMATION

Infer from existing data what the costs are when persons with disabilities are left out, for example from health care, or in this case, disaster risk reduction.

Physically visit and count: to provide for example an average of how many evacuation routes and shelters are accessible, how many have adapted facilities and assistive devices, medication and so on.

Look for information when it is urgently needed, for example specific health services or providers of parts for assistive devices that may be damaged during a disaster.

Use information from mapping exercises (see below), including who is responsible for what (e.g. ministries, NGOs, INGOs), where, how these are interconnected (if at all) and what the gaps are. These can also be quantified.

Develop your own indicators to measure inclusion in humanitarian and DRR interventions and also the extent to which laws, including international frameworks that the country signed up to (e.g. the CRPD) are being adhered to and fulfilled, and which can provide a strong argument in lobbying for inclusion.

Collect data and conduct assessments that are disaggregated by age, gender, type of disability, location and ethnicity among others to build a working database that does not exclude anyone.

Develop your own systems: for example, a project in Bangladesh developed a scoring system to see who really needs a cash top up, then used this data to lobby the cash assessment group at a national level.¹⁵

Overall, information needs to be usable and accessible by all, notably persons with disabilities and their respective organisations. Learning should also be shared, whether through meetings or material such as guidelines, which can then be taken on and developed further by others. Keep in mind that during a disaster, data stored electronically or online might not be accessible, so think of a back-up plan!

Tip! When is it best to collect data?

Immediately after a disaster event, when memory is still fresh, including that of politicians. However, remember that data generation is a continuous process.

¹⁵ See CDD, DRR and CBM (2020) [Disability Inclusive Cash Transfer: Lessons from the humanitarian response to Cyclone Amphan](#).