4. Left out of the loop: older people and persons with disabilities

Humanity – the very essence of humanitarian action and the first humanitarian principle – dictates that human suffering must be prevented and alleviated wherever it is found.[1] Moreover, the principle of impartiality prioritizes humanitarian assistance according to need, regardless of other factors such as nationality, race, political affiliation or class. Neglecting to make humanitarian assistance available and accessible to the people in most acute need not only fails to abide by humanitarian principles but also increases their vulnerability – leaving them even poorer, more at risk in the face of future shocks, and even further behind.

People most at risk of experiencing the impact of crises do not always receive the assistance and information they need in a manner that meets their needs. In some cases, people may be unable to access assistance because of the sheer complexity of humanitarian action and the chaotic operating environments of disasters and conflicts. Beyond that, there are technical reasons that prevent certain people from receiving adequate humanitarian assistance. For example, a lack of quality baseline data on the differing needs and capacities of people affected by an emergency, or limited staff/volunteer awareness and capacity to respond to the needs of particular groups.

Even the most basic information about what humanitarian assistance is available and how it can be accessed may fail to reach the very people who need it most when communications are poorly adapted to the needs of different groups. These may include linguistic minorities, people with low literacy and people who have less access to differing forms of communication or who may be less tech savvy. People less likely to leave their homes – persons with disabilities, older people, people with family responsibilities, women who may not leave their home unaccompanied for cultural reasons – will need information and assistance to be provided in different ways.

There are many other groups who could potentially fall into this 'left out of the loop' category, including people with no or low literacy, people who do not speak the predominant

1.   Humanitarian principles are derived from the Fundamental Principles of the International Red Cross and Red Crescent Movement, proclaimed in Vienna in 1965 by the 20th International Conference of the Red Cross and Red Crescent Movement (see ICRC, 1979).

language, and people without access to different forms of media, internet or familiarity with new technologies. To illustrate some of the barriers to inclusive humanitarian action, as well as efforts underway to overcome them, this chapter looks in particular at two groups of people who are frequently left out of the loop during crisis planning, response and recovery: older people and persons with disabilities. These two groups represent a large and growing proportion of the population in crisis-affected contexts; and research highlights the disproportionate impact that crises can have on them; as well as their repeated marginalization in responses to emergencies.

Covering the two groups together does not infer that they are one and the same however. While there is some overlap between the two, they are also distinct in various ways. Neither are they in themselves homogenous categories – as well as individual and contextual differences, there are different types and severities of disability for example, and significant differences between sub-groups within the over-60 population.

While focusing on older people and persons with disabilities for the purposes of illustration, this chapter seeks to draw broader conclusions about what progress, if any, has been made in terms of furthering access to aid for people left out of the loop. It examines whether the barriers to making humanitarian response more inclusive to people with particular needs remain, and what good practice there is to ensure that typically marginalized groups are able to fully participate in and benefit from inclusive humanitarian action.

4.1   How are older people and persons with disabilities affected by disasters?

Older people and persons with disabilities are not inherently vulnerable to disasters. In both categories there are a range of levels of vulnerability as well as capabilities. Indeed, there is considerable evidence of older people and persons with disabilities acting as an important resource for their families and communities, particularly during times of crisis (IFRC, 2007; WHO, 2008; Wells, 2005; Williams, 2011). There are, however, factors associated with ageing and disability that can increase vulnerability to the impact of disasters and other crises. Reduced mobility, diminished employment opportunities, chronic health conditions, discrimination and other factors may put older people and persons with disabilities more at risk during times of crisis.

Box 4.1   Definitions

The UN defines an older person as someone above 60 years of age, and 'oldest-old' generally refers to people over 80 (Wells, 2005). The same definition is used here, while also recognizing that there are sociocultural aspects to ageing that strict definitions tend to ignore, such as status in the family, physical appearance and health.

The most widely accepted and commonly used definition of disability can be found in the UN Convention on the Rights of Persons with Disabilities (UN, 2006).[2] In relation to humanitarian action, the Charter on the Inclusion of Persons with Disabilities, launched at the World Humanitarian Summit in 2016, uses much the same definition. It states "persons with disabilities include those who have long-term physical, psychosocial, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in, and access to, humanitarian programmes". This definition emphasizes that disability is not solely a personal attribute but rather the interaction between a person and their environment, which can create barriers to their participation and inclusion. References to persons with disabilities in this chapter are based on this definition.

### 4.1.1   How many people are affected?

The number of older people in the world is rapidly increasing. In 2017, there were around 600 million people aged over 60 – around 8% of the world's population. By 2100, this is expected to increase to 2.5 billion people, or 22% of the projected world population.

According to available data, the proportion of people over 60 is lower in environmentally vulnerable and politically fragile countries than the rest of the world.[3] Projections show that the gap is set to narrow. In 2015, there were an estimated 68 million people aged over 60 in environmentally vulnerable and politically fragile countries, representing 3.5% of the total population. This figure is expected to rise to 917 million by 2100, by which time people aged over 60 are expected to represent 16.5% of the total population in those countries (see Figure 4.1).

It is not immediately clear why this gap is narrowing. One factor is likely to be the increasing incidence of crises in middle-income countries where life expectancy tends to be higher (HelpAge International, 2016). No matter the cause, the projected trend has significant implications for those planning for and responding to crises, particularly given that the frequency of disasters caused by natural hazards is projected to increase and taking into account the ongoing protracted nature of the world's conflicts.

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2.   In the convention, persons with disabilities are defined as persons "who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

3.   A list of countries considered particularly environmentally vulnerable is used throughout this report's analysis. These are defined using the INFORM Index for Risk Management data set, and are those scoring above a certain threshold according to two criteria: 1) lack of coping capacity (medium, high or very high); and 2) natural hazard score (high or very high). Politically fragile countries are defined as 'fragile states and economies' in the OECD report, *States of Fragility 2016*.

Fig. 4.1   Projected ages of people living in environmentally vulnerable and politically fragile
             countries, 2000–2100
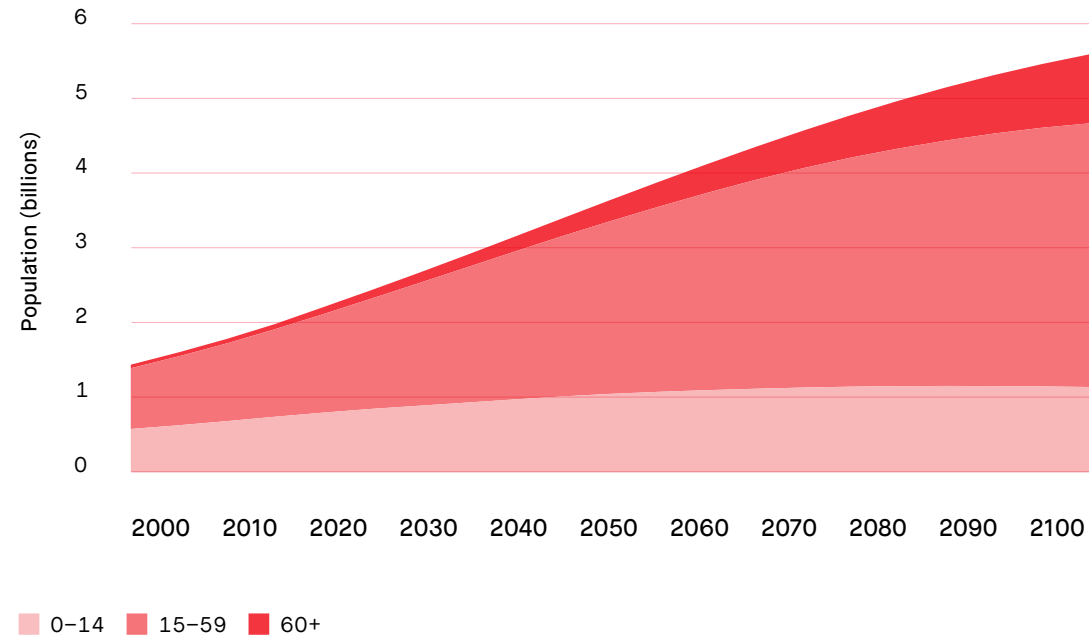
Notes: Medium demographic projections are used.

Sources: Based on UN Department of Economic and Social Affairs (UNDESA) Population
Division, INFORM Index for Risk Management 2018 and OECD *States of Fragility*.

The data suggests there are 1 billion people in the world with some form of disability –
just under 14% of the global population.[4] Within this total there are of course significant
variations in type and severity of disability. The proportion of people living with disabil-
ity is higher in environmentally vulnerable countries, with an estimated prevalence rate
of just under 17% (177 million people).

However, there are significant gaps in the data, and the number and proportion of per-
sons with disabilities are likely to be much higher, both in terms of counting persons with
pre-existing disabilities and new disabilities caused by the crisis. In countries that have
conducted disability surveys, data exists but may be outdated and the numbers are hard to
compare due to the different definitions and methodologies used. A cursory look at disa-
bility survey data, however, shows its value compared with more general national data col-
lection exercises. Data for 31 countries using national census data (for various years) shows
an estimated disability prevalence of 3%. The prevalence rate for those same countries

combined rises to over 21% using data from the World Health Survey 2002–2004, gath-
ered using a more specific and detailed set of questions on disability (WHO, 2004).

Many people categorized as having a disability are also older people. As the population
of older people continues to grow, age-related health problems affecting sight, hearing,
mobility and mental functioning will undoubtedly have a significant effect on the preva-
lence of disability. Figure 4.2 shows the already-high proportion of persons with disabilities
(including severe disabilities)[5] in the older age group compared with younger age groups.

Fig. 4.2   Intersection between older people and persons with disabilities, 2002–2004
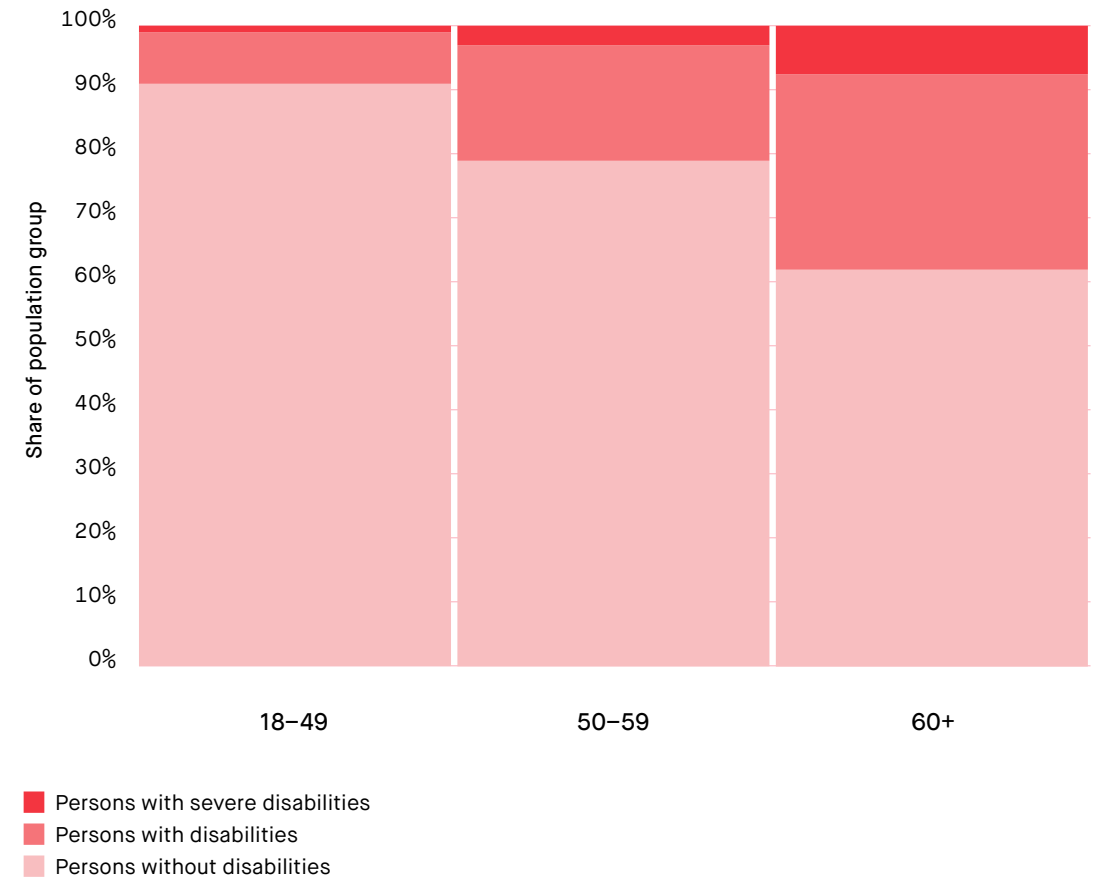
Notes: Disability and severe disability are defined by an item response theory score of 40+ and
50+ respectively.

Source: WHO (2011) Technical Appendix

4.   Figures are based on a range of national and international sources including: UN Economic and Social Commission for
      Asia and the Pacific Disability at a Glance (2017), WHO *World Disability Report 2011*, Demographic and Health Surveys
      repository, Eurostat European Health Interview Survey, Barbados 2010 Population and Housing Census, Brazil 2010
      Population Census, 2012 Canadian Survey on Disability, Guatemala National Disability Study 2016, US Census Bureau
      Disability Statistics 2017, Zambia Living Conditions Monitoring Survey 2006 and UN Department of Economic and
      Social Affairs Population Division. Different sources may include different types and extents of disability.
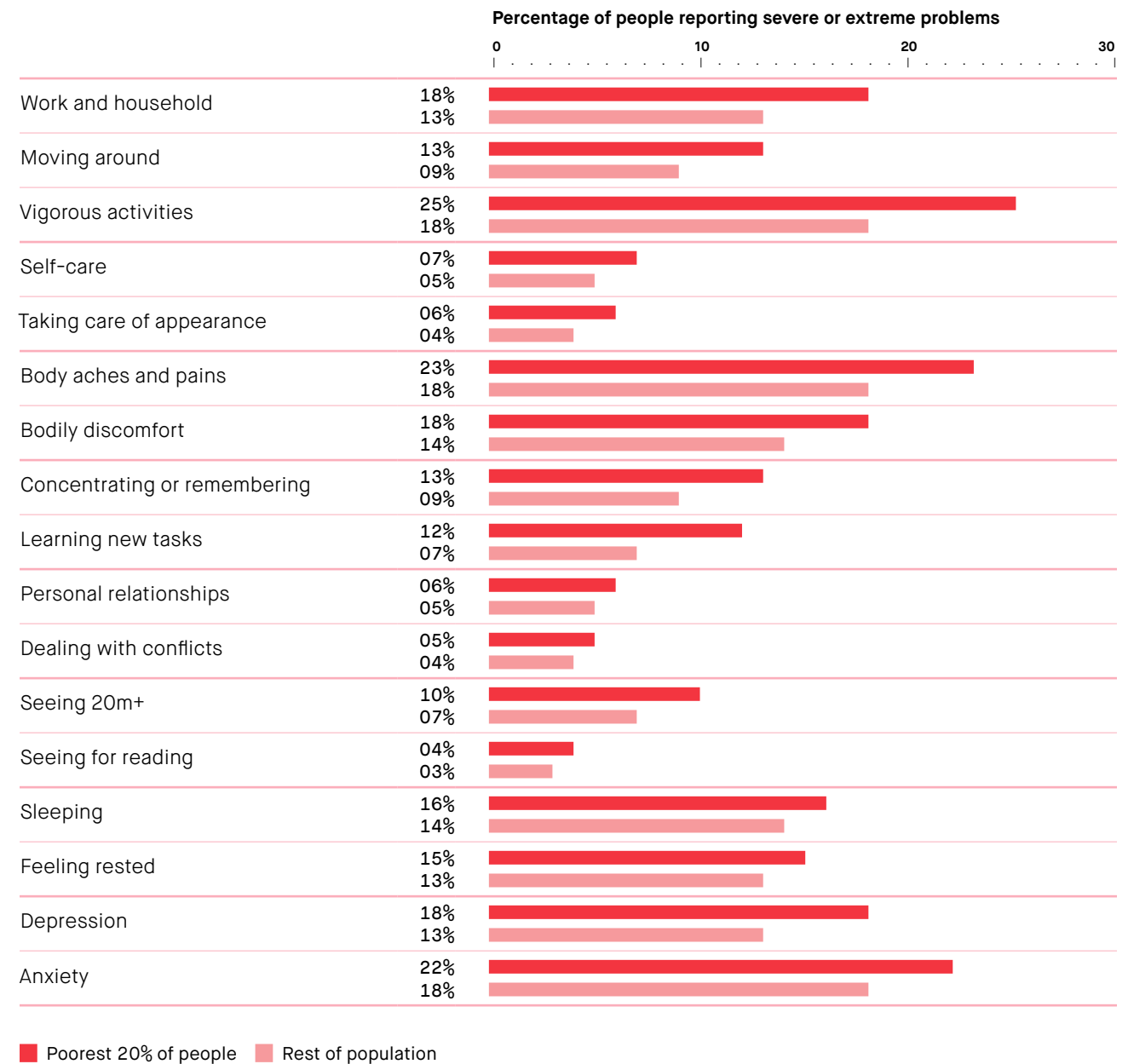
5.   The definition of 'severe disability' from WHO *World Report on Disability 2011* references the Global Burden of Disease
      Study and specifies it is the equivalent of disability inferred for conditions such as quadriplegia, severe depression or
      blindness.

4.1.2 How are people vulnerable to and affected by disasters?

Neither old age nor disability are stand-alone determinants of vulnerability. Vulnerability in emergencies can come from the combination of age or disability with other factors, such as gender, ethnicity or social exclusion. Poverty is a key factor in determining vulnerability to the impact of crises. Research indicates that older people and persons with disabilities are more likely than their younger and non-disabled peers to experience poverty. This can be due to their particular needs, for example healthcare needs and expenses (HelpAge International, 2018), as well as barriers in their environment that prevent them from accessing key services and opportunities, such as education, healthcare, employment, justice and social support (DFID, 2015; HelpAge International and Handicap International, 2012; Rohwerder, 2015). This reinforces and increases the vulnerability of older people and persons with disabilities during times of crisis, leaving them with fewer resources to withstand and recover from shocks and pushing them further into poverty. In Bangladesh, the data shows a correlation between poverty and disability in a context of high vulnerability to natural hazards, including floods, tropical cyclones, storm surges and droughts. These hazards combined with an extremely dense population leave many people in Bangladesh vulnerable to the impact of disasters caused by natural hazards. The Internal Displacement Monitoring Centre estimates that over 4.7 million people were newly displaced by rapid-onset, weather-related disasters in Bangladesh between 2008 and 2014 (IDMC, 2015). People reporting severe or extreme problems in a range of different categories associated with disability are considerably higher for the poorest 20% of the country's population (see Figure 4.3).[6]

Fig. 4.3   Poverty and disability in Bangladesh

Percentage of people reporting severe or extreme problems

Category	Poorest 20%	Rest
Work and household	18%	13%
Moving around	13%	09%
Vigorous activities	25%	18%
Self-care	07%	05%
Taking care of appearance	06%	04%
Body aches and pains	23%	18%
Bodily discomfort	18%	14%
Concentrating or remembering	13%	09%
Learning new tasks	12%	07%
Personal relationships	06%	05%
Dealing with conflicts	05%	04%
Seeing 20m+	10%	07%
Seeing for reading	04%	03%
Sleeping	16%	14%
Feeling rested	15%	13%
Depression	18%	13%
Anxiety	22%	18%

■ Poorest 20% of people   ■ Rest of population

Notes: See WHO *World Report on Disability 2011* for detailed descriptions of the different categories associated with disability.

Source: Based on WHO *World Report on Disability 2011*

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6.   The methodology used in the WHO *World Report on Disability 2011* differs from that used by the Washington Group on Disability Statistics. WHO uses an item response theory score model based on individual disability surveys which use a range of questions similar, but not identical, to the Washington Group Short Set of Disability Questions.

Crises can have a disproportionate impact on older people and persons with disabilities. A study by the Office of the UN High Commissioner for Human Rights in 2015 uses data from Japan to suggest that persons with disabilities are four times more likely to die when a disaster strikes (OHCHR, 2015). In Vanuatu, research indicates that persons with disabilities were more than twice as likely to have been injured during Tropical Cyclone Pam in 2015 (CBM, 2017).

In the Philippines in 2013, people over 60 represented approximately 7% of the population, but accounted for 38% of the fatalities caused by Typhoon Haiyan that same year (see Figure 4.4). Similarly in Nepal, 29% of people who died in the earthquake in 2015 were aged over 60, yet older people represented only 8% of the population.

Limited mobility, making it difficult to flee, is likely to be the primary reason for the disproportionate impact of crises on older people and persons with disabilities. However, there are other reasons specific to each context that help to explain the data. In some cases, people may have nowhere to go and prefer to stay close to home despite the risks. Others may underestimate the impact of crises based on their previous experiences. Research also suggests that older persons with disabilities disproportionately experience poor housing conditions (HelpAge International, 2018), which may put these people more at risk in the event of disasters caused by natural hazards.

Fig. 4.4   Age breakdown of people affected by disasters in the Philippines and Nepal
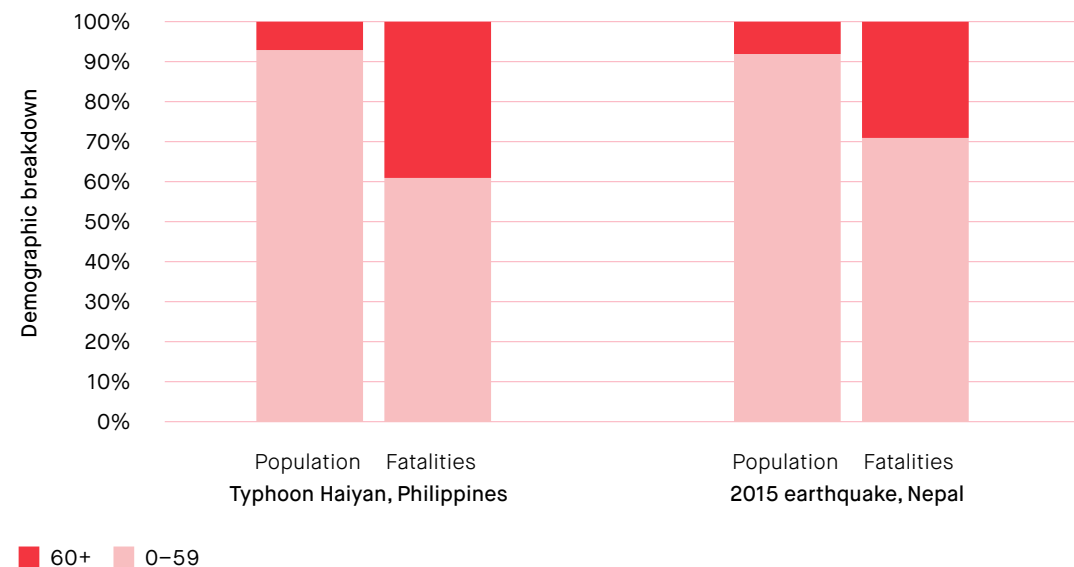
Source: Based on UNDESA Population Division and HelpAge International (2016, 2013)

Beyond fatalities, disasters can and do impact on older people and persons with disabilities in particular ways. These include the infliction of new injuries and subsequent loss of mobility; reduced access to medical services for chronic non-communicable diseases, such as cardiovascular disease, stroke, diabetes and dementia; increased risk from infectious diseases; nutritional deterioration; distress, depression and anxiety; and loss of livelihoods.

One of the most commonly cited impacts of disasters on older people and persons with disabilities is the breakdown of family and community support structures, leading to potentially increased protection risks such as rape and sexual abuse, abuse more broadly, and strong feelings of isolation and exclusion (Burns and Oswald, 2014; UNHCR, 2017c).

Box 4.2   Isolation of older people in Mongolia

For centuries, people in Mongolia have lived as nomadic herders, moving their animals regularly to get the best of the summer grass. This traditional lifestyle has begun to change, however, with increasing migration to urban areas, leaving many older people who stay behind to take care of livestock separated from traditional support systems and isolated from family members.

Mongolia experiences frequent *dzuds* – a phenomenon whereby extreme temperatures in both summer and winter leave many animals short of food and expose herders to food shortages, lack of fuel and deterioration of their health. An extreme dzud in the winter of 2016/2017 affected many herders. This included a significant proportion of older people who had become isolated due to younger members of the family moving to urban areas in search of work. Losses of livestock led to intense stress for many people as well as feelings of shame and failure. Ultimately, the disaster is estimated to have affected around 225,000 people and killed over one million animals.

The humanitarian response to the *dzud*, both from national and international institutions and organizations, largely focused on providing food, fuel, fodder and veterinary medications. Few organizations focused on the particular needs of older people and persons with disabilities. The Mongolian Red Cross through its Social Inclusion and Development Programme did, however, explicitly identify older people and persons with disabilities as vulnerable groups in need of specifically tailored support. Their assistance included helping people to carry out household chores, access state benefits and arrange medical visits continue healthcare for chronic illness and disease.

Social contact to respond to feelings of isolation was also a strong element of the Mongolian Red Cross response. It took various forms, including reading to older people and persons with disabilities, informing them of news from outside, and offering someone to talk to and a source of advice and comfort during the crisis. This enabled people who may otherwise have been excluded from the response to benefit – not only by receiving physical assistance, but also in countering feelings of loneliness and the negative impact of social exclusion.

The disproportionate impact of crises on older people and persons with disabilities can be caused by various factors, including limited mobility, dependence on family and community members, stigmatization and inaccessibility of early warning messaging and evacuation facilities. Disasters and conflicts can also increase the number of people living with disabilities, due to new injuries as well as deterioration of existing conditions. For people with both new and existing disabilities, the negative impact of disasters may be compounded by loss or damage to assistive devices in the midst of an emergency, limited

access to healthcare and rehabilitation, psychological stress and anxiety, abandonment, and a breakdown of support structures and preventative healthcare.

Certain risk factors can contribute to the impact of disasters on people, many of them related and overlapping. For example, disability combined with other factors can increase levels of risk and vulnerability. A study by Humanity & Inclusion found that 27% of persons with disabilities consulted had experienced secondary trauma as a result of being psychologically, physically or sexually abused after the disaster (Humanity & Inclusion, 2015).

Women and girls with disabilities may be particularly vulnerable to abuse in post-crisis contexts. Global data indicates that women and girls with disabilities are almost ten times more likely to experience sexual violence than persons without disabilities (Humanity & Inclusion). A study by the Women's Refugee Commission found that women and girls with mental and intellectual disabilities were perceived to be most at risk of sexual violence in crisis environments (Women's Refugee Commission, 2015). Consultations with refugee populations showed that men and boys with disabilities, while not as at risk as women and girls, are also targeted for sexual violence (Women's Refugee Commission, 2016). A breakdown of social and protective networks, isolation, family stress, a lack of safe housing, overcrowded living conditions and changes in gender roles brought about by an emergency can all combine to increase the vulnerability of women, girls, men and boys with disabilities in crisis situations, as well as their caregivers (Women's Refugee Commission, 2015, 2016) (see Chapter 2, section 2.3).

4.1.3   Capacities and contributions during disaster response

As well as the needs, the capacities of older people and persons with disabilities are frequently overlooked in emergency contexts. The two groups are typically characterized as helpless or weak during times of crisis. Indeed, while some older people and persons with disabilities may face additional risks in the event of a disaster, they also often have valuable contributions to make and are keen to regain control of their lives and stabilize the lives of their families and wider communities.

For example, many older people, including persons with disabilities, take on additional childcare responsibilities in times of crisis – women in particular (Wells, 2005). Migration can make this the norm in some contexts, where younger people seek employment elsewhere, leaving older people to take care of grandchildren. The phenomenon of 'skipped generation families' is also a feature in places heavily affected by HIV and AIDS and other epidemics (Williams, 2011). Indeed, even outside of situations of crisis, grandparents and older children – especially women and girls – often provide unpaid childcare in countries with insufficient and unaffordable formal childcare provision (ODI, 2016).

Box 4.3   Older people as agents of change

Afghanistan has been in a state of protracted conflict for decades and many parts of the country are at high risk of natural hazards. This combined with geographical barriers has left many millions of people with limited or no access to essential health services. The maternal mortality ratio for Afghan women is among the highest in the world. Cultural norms in Afghanistan dictate that a woman must be seen by a female health professional, and women cannot travel alone to seek medical attention without an accompanying male family member. As a result, home births are still the norm with 86% of deliveries taking place at home.

The Afghan Red Crescent Society runs specially designed community-based health programmes (CBHP) across Afghanistan. These bring critical healthcare to vulnerable communities by providing services, health awareness and promotion, improved access to safe drinking water and improved sanitation facilities, and more diverse foods.

The CBHP has adopted an innovative way of convincing pregnant women – and their husbands, fathers and other male relatives – to seek health services and undergo medical treatment in the nearest health facility. Grandmothers are often considered as influential figures not only in their own families, but also in wider rural communities. Therefore, local committees of grandmothers were formed and trained to play a key role in advocating for women (and particularly pregnant women) to seek better healthcare and for men in the community to support and enable them to do so.

The CBHP in Balkh set up ten committees in 2016 with a membership of around 200 women. An evaluation of the project in 2017 found that the grandmothers' committees had a strong positive effect on raising awareness of improved maternal health practices. During the CBHP, there was a significant increase in deliveries attended by a skilled health worker: in pilot areas, from 4% in 2008 to 25% in 2010, and in all project areas from 30% in 2008 to 66% by 2016. The improvements cannot be attributed solely to the grandmothers' committees, but they are credited with making a significant contribution to changing mindsets and encouraging healthy practices.

Overall, the project succeeded in identifying and harnessing the unique capabilities of older people – and older women in particular – as volunteers in their communities, and did so in a creative and dignified way to bring about positive change. The wider implementation of integrating the Afghan Red Crescent Societies' CBHP, mobile health services and maternal, neonatal and child health clinical services all aim to widen service reach with holistic, curative, preventive and promotional healthcare to targeted vulnerable communities. Engaging communities in health service implementation and community acceptance aims to ensure safe access and assurance of protection for staff and volunteers operating in insecure areas. Continuous support to build the capacity of communities and volunteers leads to greater community resilience in coping with health and disaster risks.

Not only do crisis risk management activities frequently ignore disability, but persons with disabilities and their caregivers are rarely given the chance to contribute to early warning systems and other disaster preparedness-related initiatives. There are examples, however, of people using their own insights on disability to make valuable contributions to risk reduction efforts.

Contributions from persons with disabilities
to disaster management planning

The Dumaguete Effata Association of the Deaf (DEAF) in the Philippines is implementing a programme to increase access to hearing-oriented disaster risk reduction, disaster management and emergency response programmes. It recognizes that spoken and written materials, and sound-based early warning systems such as sirens or alarms, generally fail to alert persons who are deaf to the dangers of oncoming disasters. DEAF is working with the public sector to produce a Filipino Sign Language lexicon for climate, disaster and related signs for inclusion in visual early warning materials. The organization is also developing hazard maps of persons who are deaf in environmentally vulnerable areas, along with corresponding disaster response protocols, and facilitating collaboration and training for stronger community participation to institutionalize disability-informed policies and practices.

The DEAF team have mobilized networks for deaf person's organizations and are working with local government units responsible for disaster risk management and disaster preparedness programmes. As such, the outputs from the project not only respond to the needs and capacities of persons who are deaf, but the initiative allows them to take up active roles in advocating for more attention to persons with disabilities in disaster management processes.

4.1.4   What can be done to facilitate access to, and participation in, humanitarian response?

A range of barriers prevent older people and persons with disabilities, as well as other population groups, from equitably accessing humanitarian assistance and actively participating in the response. These differ from the technical and operational (see sections 4.2–4.5) to the more systemic and underlying challenges and constraints. First and foremost is the failure to fully implement the various standards, frameworks, policies and guidelines that already exist to protect and promote the rights of groups who are particularly at risk, including older people and persons with disabilities.

Overarching commitments in the Sustainable Development Goals (SDGs(include implicit and explicit references to prioritize outcomes for marginalized groups. Similarly, the Sendai Framework for Disaster Risk Reduction 2015–2030 refers to older people in its list of relevant stakeholders for working together on preventative approaches to disasters, and commits to establishing persons with disabilities as key stakeholders in planning for and implementing risk reduction strategies.

There are also several important international frameworks and commitments focused on persons with disabilities and older people that guide the efforts of governments, organizations and people. The UN Convention on the Rights of Persons with Disabilities is a cornerstone for recognizing the human rights of persons with disabilities and also promoting a rights-bases approach during humanitarian emergencies. The more recent Charter

on the Inclusion of Persons with Disabilities in Humanitarian Action sets out clear commitments to lift the barriers that keep persons with disabilities from accessing humanitarian services.[7]

The 2002 Madrid International Plan of Action on Ageing aims to strengthen respect for the rights of older people. While normative rather than binding, the plan covers a wide range of issues associated with ageing populations, including emergency situations, and has been adopted by 159 governments.

It is undoubtedly positive that these global frameworks and commitments exist. However, the track record of humanitarian actors – international and national – in putting them into practice, and ensuring the availability of funding to do so, is questionable.

Some countries have made progress in mainstreaming the rights of older people and persons with disabilities into national policy frameworks. Current research by the International Federation of Red Cross and Red Crescent Societies (IFRC) in Asia and the Pacific shows that vulnerable groups, including older people and persons with disabilities, are often prioritized in disaster risk management legislation. However, overall national disaster laws and systems are generally weak on protection and inclusion issues and tend to include general provisions about engagement and inclusion without specific mandates, details and commensurate resources to bring about tangible action and benefits. Moreover, the focus tends to be on addressing needs rather than ensuring the active participation of older people and persons with disabilities in decision-making processes.

Humanitarian organizations and donors have also developed their own policies and tools for better including older people and persons with disabilities in their portfolios and programmes. The Humanitarian inclusion standards for older people and persons with disabilities *(*Age and Disability Consortium, 2018) is a particularly important new initiative designed to strengthen collective organizational capacity on behalf of older people and persons with disabilities in situations of crisis.[8] And the forthcoming Inter-Agency Standing Committee Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action are expected to assist humanitarian responders, governments and affected communities to coordinate, plan and implement the effective participation and inclusion of persons with disabilities in humanitarian contexts.

Consultations with mainstream humanitarian and development organizations, however, raise questions about the extent to which such tools and guidelines are being used. Some organizations have voiced concerns about their capacity to mainstream a long list of cross-cutting issues and absorb a growing set of tools and guidance materials. Others question the prioritization of older people and persons with disability alongside other vulnerable groups; while others still are willing in principle to take on the challenges of age and disability inclusion, but fear a lack of specialist expertise and dedicated resources

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7.   See WHO (2018b) for more detail on its work on improving access to assistive technology for people in need.

8.   The Minimum Standards for Age and Disability Inclusion in Humanitarian Action were developed as part of the Age and Disability Capacity Building (ADCAP) programme, led by HelpAge International as part of a portfolio of capacity strengthening projects under the Start Network. The Age and Disability Capacity Building (ADCAP) programme is an initiative of the Age and Disability Consortium, a group of seven agencies working to promote age and disability inclusive humanitarian assistance: CBM, DisasterReady.org, Handicap International, HelpAge International, IFRC, Oxford Brookes University and RedR UK.

in their organizations will prevent them from doing so effectively (WaterAid et al, 2016). Some organizations are visibly committed to improving age and disability inclusion at headquarters, but find that practice at country level is lagging behind. In other cases the opposite is true, with good practice ongoing in crisis contexts but a lack of headquarters support to systematically scale up effective age- and disability-inclusive approaches.

The following sections focus on some of the more technical challenges that continue to act as barriers to including vulnerable groups in humanitarian response, focusing on older people and persons with disabilities.

4.2 Data and situational information

Exclusion of older people and persons with disabilities from humanitarian action begins with a lack of data and situational information. The poor state of secondary data, pressures to respond quickly in emergency situations, and an inability to tailor programmes to the needs of specific groups all act as barriers to the effective collection, analysis and use of data on older people and persons with disabilities.

If people designing and conducting needs assessments do not consciously collect age- and disability-disaggregated data, or seek and use pre-existing data, then older people and persons with disabilities are less physically visible as populations in need. Those responding to the emergency are thereafter less driven to design age- and disability-appropriate programmes and services, and less accountable to do so if the needs of older people and persons with disabilities remain largely unknown.

Where data on older people is gathered, the over-60s age group is often treated as homogenous, failing to recognize the often-significant differences between sub-groups: 60–69 years, 70–79 years and so on (HelpAge International and IDMC, 2012). Cut-offs and age limits in surveys also restrict comprehensive data gathering on the needs of older people. There is very little economic and income-related data on older people, for example, partly due to the assumption that older people are dependent rather than working (Development Initiatives, 2017a). Similarly, older people are rarely a target group for surveys related to nutrition – commonly focused exclusively on children under five, or HIV prevalence – which tend to focus on people of reproductive age (HelpAge International and IDMC, 2012).

When older people are asked about their situation and their responsibilities, the results can be surprising. In Bangladesh in 2017, a rapid-needs assessment of older people forcibly displaced from Myanmar found that 72% of the older people interviewed had responsibilities to care for an average of 3.2 dependants in the household (HelpAge International, 2017). This information challenged the assumption that older people are automatically dependants in the family. In this instance it also helped to inform the design of programmes that not only provided appropriate support to older refugees, but worked with older people as conduits for ensuring adequate healthcare, protection and other essential services to children in the refugee population.

Collection, analysis and use of disability-disaggregated data in humanitarian settings are even rarer. In some countries – including those affected by disasters caused by natural hazards, conflict and both – there is little to no data and the actual number and situation of persons with disabilities is largely unknown. A lack of data on disability can lead to underestimates of disability prevalence, making it easy for governments and humanitarian policy-makers and practitioners to overlook the needs and rights of persons with disabilities (DFID, 2015).

Box 4.5   Improving data on persons with disabilities

When humanitarian responders do collect disability data on the populations they serve, it generally derives from the use of binary 'yes/no' questions in assessments and surveys, such as "do you have a disability or medical condition?" This can lead to significant under-reporting.

Recognizing these data gaps and weaknesses, Humanity & Inclusion (formerly Handicap International) is working to improve the availability of quality data on persons with disabilities and increase its use by humanitarian organizations. Its project, *Disability Statistics in Humanitarian Action,* is piloting collecting better and more reliable data on persons with disabilities in three countries: Jordan, the Democratic Republic of Congo and the Philippines. Thirty organizations – UN, international non-governmental organizations (NGOs) and local NGOs – are participating in the pilot.

The project promotes the use of the Washington Group Short Set of Disability Questions in humanitarian contexts (Washington Group on Disability Statistics, 2018). The questions were originally designed for national censuses, and to allow for international comparability of disability statistics. They enable data collectors to gather information on the level of difficulty people report in carrying out activities is six basic areas: seeing, hearing, mobility, remembering, self-care and communicating.

Washington Group Short Set of Disability Questions

Do you have difficulty **seeing**, even if **wearing glasses**?

Do you have difficulty **hearing**, even using a **hearing aid**?

Do you have difficulty **walking** or **climbing steps**?

Do you have difficulty **remembering** or **concentrating**?

Do you have difficulty (with **self-care** such as) **washing all over** or **dressing**?

Using your usual language, do you have difficulty **communicating**, for example **understanding** or **being understood**?

The pilot is in its first year but already generating interesting results. In Jordan, for example, UN High Commissioner for Refugees (UNHCR) asked a small group of people the questions during registration. Data from the exercise indicated a significantly higher prevalence of disability in the refugee population than previously thought. Of the sample group, 27.6% of refugees had some form of disability according to responses given to the Washington questions, compared with a disability prevalence rate of only 2.4% using UNHCR's own registration processes.

Experience from the project so far indicates that there is significant demand for a tool to identify persons with disabilities. However, adapting backend information management systems to host the data can be slow and complex, especially in larger organizations. Data sharing is also an issue, and organizations need reassurance of data protection and confidentiality. Use of the data is another area that needs more attention – considering how the data can be used to inform more inclusive programming – rather than gathering data as a tick box exercise, perhaps to satisfy donor requirements, then continuing to design programmes in the same way as before.

Given the obvious intersectionalities in human identity – the differences between individuals and groups and how they combine to shape different experiences of access, power and oppression (Slim, 2018) – there is a clear need to bring different workstreams together and combine efforts on various cross-cutting issues, including gender, age and disability. That said, data on different people's facets is rarely combined to create a more holistic picture of the situation and needs of particular groups. While the logic for collecting data disaggregated by sex, age and disability is by now well understood and accepted, its implementation is less consistent (Age and Disability Consortium, 2015).

4.3   Tailoring assistance

Without a sound evidence base and justification for including older people and persons with disabilities in programmes and approaches, institutions and organizations responding to disasters often unwittingly exclude these groups from accessing assistance. Deliberate choices to prioritize certain groups over others – driven by mandates, biases and assumptions, or resource constraints and other factors – also limit the extent to which older people and persons with disabilities are included in broader programmatic responses or prioritized for tailored assistance.

Examples of exclusion include distribution plans for relief items that fail to take into account the strength and stamina of older people or the mobility of persons with disabilities. Similarly, food items distributed following disasters are not always appropriate for the diets and nutritional status of older people, and medications for non-communicable diseases are rarely prioritized. Livelihoods is another area that largely excludes older people in crisis and post-crisis settings, based on the assumption that people over the age of 60 are 'too old' to work and are not expected to contribute to the household income. This is often not the case, particularly given the significant proportion of older people in

the world today – just over half and rising – who have no access to pensions (UNDESA, 2017). Moreover, many older people continue to act as key decision-makers in their families and communities, particularly during times of crisis – something that is not often recognized and capitalized on by people responding to emergencies.

Data from a survey conducted by Humanity & Inclusion in 2015 reveals startling levels of exclusion from humanitarian assistance and services for persons with disabilities. Of respondents to the survey, all of whom had some form of disability, 70% indicated that health services were a priority for them in the event of a crisis; yet only 33% said the services were available during a crisis. The results were similar for other sectors, such as water, shelter and food; and other sources indicate that access to mental health services is a particular gap. In addition, services targeted at the needs of persons with disabilities, such as rehabilitation and assistive devices, were only available to between 24 and 31% of survey respondents (Mirza, 2011). Data from WHO, while not specific to humanitarian contexts, also indicates that only one in ten people globally has access to assistive technology, such as hearing aids, wheelchairs, communication aids, spectacles or prostheses.[9]

Box 4.6   Ensuring accessibility of assistance and services to older people during disasters

Kenya was affected by severe drought in 2017, triggering a national emergency. Prolonged dry spells resulted in poor crop performance and even crop failure in some regions, threatening local food security and causing health problems.

Data from a needs assessment for the drought response by the Kenya Red Cross Society revealed that a significant proportion of older people and persons with disabilities were not reaching food distribution and medical outreach sites to access much-needed services. Further analysis showed that many older people had been left behind without carers when families had moved in search of pasture and clean water. This left them without access to services and at risk of malnutrition, particularly people with mobility challenges who were unable to travel long distances.

The Kenya Red Cross Society worked through community health volunteers and disabled person's organizations (DPOs) in Turkana county to map and identify households with older people and persons with disabilities. This strategic targeting allowed the team to identify an accessible venue, provide services and ensure the logistical requirements allowed access to the medical camp facilities for people with mobility challenges. As a result, out of the just over 5,500 people reached, around 1,760 were classified as older people and 649 as persons with disabilities.

The experience in Turkana county was made possible thanks to a clear disability and social inclusion policy, and a determined effort by the Kenya Red Cross Society to gather and analyse sex, age and disability-disaggregated data using well-trained

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9.   The Charter was launched at the World Humanitarian Summit in 2016 and has since been endorsed by a number of states, UN agencies, civil society organizations and networks. According to a recent update, over 150 stakeholders representing over 1,000 organizations have endorsed it (Handicap International, 2017).

> staff. It was also enhanced through close collaboration with local DPOs, which helped identify vulnerable groups who could then actively participate.

4.4 Effective communication

Lack of information on available services can be a major barrier to inclusion and accessibility. Participatory research by HelpAge International in Lebanon, South Sudan and Ukraine in 2015 found that more than two-thirds of older people felt that they did not have enough information about the humanitarian assistance available to them (HelpAge International, 2016).

Information on available services in disaster situations can fail to reach older people and persons with disabilities for various reasons. The two groups may not be seen as priority targets for assistance; therefore, those responding do not necessarily reach out with the necessary information. Communication methods and channels may also inadvertently exclude older people and persons with disabilities. For example, written communications or SMS messages may not be suitable ways of communicating with older people with high levels of illiteracy and/or minimal use of mobile phones. People with vision, hearing and mobility limitations may have additional difficulties receiving and processing critical information about eligibility and procedures for accessing assistance. Overlooking even the most basic of considerations, such as the height and location of information boards to ensure that they are wheelchair-accessible, can limit access to vital information for persons with disabilities (IFRC, 2015).

Communication is not a one-way process: a two-way flow of information is important to ensure people affected by crises are able to provide feedback or complain about the way assistance is being provided. This includes considering how older people and persons with disabilities who are housebound can provide feedback, for example through home visits or by telephone (IFRC, 2015a).

Innovation and technology use are helping to increase inclusion and support enablement and transform humanitarian action. However, new ways of working and communicating can risk exacerbating feelings of exclusion for some older people and persons with disabilities. In the case of cash transfer programming, for example, and particularly programmes that deliver cash through electronic transfers, it is critical that all recipients receive adequate and appropriate information about the distribution mechanism, including people with restricted literacy or limited familiarity with banking systems and associated technology (Age and Disability Consortium, 2018).

Language barriers can leave people left out of the loop. Older people and persons with disabilities who are also migrants or from linguistic minorities may nor speak the official national language(s). Women in particular often have fewer educational opportunities and therefore might be less likely to speak or read a second language. Furthermore, people tend to revert to speaking in their mother tongue in old age (Kees de Bot, 2005; Pew Research Centre, 2015; Bleakley, 2010). Despite this, the humanitarian sector consistently underestimates the language factor, further hampering the ability of minority language speakers to receive information from and communicate with humanitarian responders.

Speakers of minority languages who are not fluent in the official national language(s) are at a structural disadvantage in many countries. They often belong to less prosperous and powerful geographical regions or ethnic groups and, as a result, are more vulnerable when a crisis hits.

However linguistically diverse the affected population, humanitarian responses are usually coordinated in international lingua francas and delivered in a narrow range of national languages. Basic data on the languages and literacy levels of the affected population is not systematically collected and shared in the way that other fundamental characteristics such as gender and age might be. As a result, evidence-based multilingual communication strategies are rarely developed. The small pool of trained translators and interpreters in many underserved languages is also a limiting factor. Without data, humanitarians tend to assume a lingua franca will be universally understood. Without resources, they call on untrained members of the affected population who speak the language used by responders to plug the gap, frequently unresourced and unsupported.

A shortage of trained female interpreters with the right language skills is a particular problem. Without the ability to talk to someone of the preferred gender in their preferred language, survivors of violence and abuse, including sexual and gender-based violence, are far less likely to report incidents. People affected by disasters and service providers from Italy and Turkey to Nigeria have repeatedly described how this shortage prevents women and others who have experienced abuse getting the support they need (TWB, 2017a).

Concerted work is underway to address this problem. In the refugee response in Cox's Bazar, Bangladesh, for example, BBC Media Action, Internews and Translators without Borders are working together to build a library of resource materials and tools to support humanitarian organizations' community engagement. Everything from needs assessment surveys to community feedback mechanisms can be more inclusive when they are in the right languages and formats to include the whole of the affected community (CDAC Network, 2017).

Box 4.7   Ebola as a crisis of language

> The 2014–2016 Ebola outbreak in West Africa had a disproportionate impact on poor people, older people, people with chronic illnesses and persons with disabilities (Rohwerder, 2014). Language was an obstacle to controlling the spread of the disease. People in the affected countries knew little about Ebola and rumours spread quickly, prompting the destruction of health facilities and reliance on ineffective means of protection and treatment. Understanding what these rumours where and communities' interpretation of the outbreak was also a challenge.
>
> Information campaigns were deployed in the most-affected countries to counter the rumours with facts about how people could keep themselves safe and access effective care. But at first information was available primarily in English in Liberia and Sierra Leone and French in Guinea – although the population in these countries

speaks over 90 languages. Just 13% of women in Sierra Leone speak English (Berger and Tang, 2015). Translators without Borders' research with Ebola-related content in Kenya confirmed the impact of having information in the right language. Participants initially answered only 8% of simple questions on Ebola correctly. When shown an Ebola warning poster in English, understanding of key facts went up to 16%. With information in Swahili, it increased to 92% (TWB, 2015).

Research on the outbreak in Liberia and Sierra Leone indicates that women died in greater numbers than men, at the beginning and peak of the outbreak, in part due to their role as caregivers. They were also less likely to access both telecommunication channels and traditional channels relaying information, and to be included in communication campaigns targeting community or faith leaders (ACAPS, 2015). An early shortage of information material for non-literate audiences and speakers of local languages left significant swathes of the population in deadly ignorance.

The way messages were developed and disseminated evolved with the epidemic. Translating a range of materials, from posters to videos, into seven local languages dramatically expanded their potential reach. Language was clearly very important, but so too was how messages were passed, recognizing the different community-specific perceptions of what was happening. The development of community-led approaches including social mobilizers from the local area was a turning point in tackling Ebola in Sierra Leone (Oxfam, 2015). The local mobilizers spoke the right languages and became a trusted information source. Specialized organizations such as Humanity & Inclusion devised programmes to transmit key information about Ebola to vulnerable people and persons with disabilities (Humanity & Inclusion, 2014). Simple content communicated in local languages helped communities implement effective strategies to support sick people and prevent transmission.

4.5   Local leadership

Successfully putting existing guidelines into practice and scaling up examples of good practice requires close coordination between disability-focused organizations and mainstream humanitarian agencies. Mainstream humanitarian agencies may have good intentions for disability-inclusive planning and programming, but often lack the necessary local knowledge and technical expertise. In some cases they may also inadvertently promote negative stereotypes about disability because of their lack of understanding.

DPOs and older people's organizations (OPOs) working at all levels from grassroots to international have helped to improve the lives of their members and advocate for the inclusion of persons with disabilities and older people. At the most local level, DPOs and OPOs have unique knowledge of some of the most at-risk people and families. Their ability to advocate for full inclusion in the services being provided by mainstream humanitarian organizations in the event of large-scale emergencies, however, is limited by lack of familiarity with the international humanitarian sector and its processes, procedures and

norms, as well as a reluctance on the part of international organizations to cede power to national and local responders. In common with other local NGOs and civil society organizations, they also lack access to international humanitarian financing to effectively engage and scale-up their efforts (Development Initiatives, 2017b). Their knowledge and expertise, therefore, often goes underused.

Beyond their representative organizations, persons with disabilities and older people, as well as their caregivers, are routinely excluded from disaster risk management processes and denied the opportunity to represent themselves in matters that directly affect them. A survey of persons with disabilities conducted by the UN Office for Disaster Risk Reduction in 2015 found that just 17% of respondents were aware of a disaster management plan in their area and only 14% said they had been consulted on it (UNISDR, 2013).

Despite strong evidence of the benefits of including older people, persons with disabilities and other frequently marginalized groups in crisis-related planning, response and recovery, few humanitarian organizations recognize and capitalize on their knowledge, capabilities and resources. This may be because of biased assumptions about these groups and their limitations, or because of a lack of time and resources – either real or perceived – to understand and capitalize on their strengths. However, it is also symptomatic of top-down approaches to humanitarian response more generally, wherein people affected by a crisis are typically characterized as passive recipients of aid rather than active stakeholders in the design and delivery of aid responses (Grünewald and de Geoffroy, 2008).

Box 4.8   Bridging the gap between disability and humanitarian action

In April and May of 2015, two large earthquakes struck Nepal killing around 9,000 people, displacing thousands more, and causing widespread damage to infrastructure, services and livelihoods. In response, the Government of Nepal, together with local, national and international organizations, launched a large-scale relief effort.

As part of the response effort, and based on experiences from the Haiti earthquake in 2010 and Typhoon Haiyan in the Philippines in 2013, the international NGO, CBM, worked with the National Federation of the Disabled Nepal, the national umbrella body of persons with disabilities in Nepal, to establish 'ageing and disability focal points' in three of the worst-affected districts. HelpAge International and partners set up additional focal points in other affected districts.

The focal points operated as specialized hubs, identifying people with particular needs in the affected population and matching them with existing service providers across a range of different sectors, including water, sanitation and hygiene, food, shelter, health, education and livelihoods. The points were staffed directly by persons with disabilities who worked in their communities to ensure assistance reached the people most in need. In certain cases, for example for women with disabilities who faced extra challenges related to discrimination and additional domestic responsibilities, volunteers and social mobilizers conducted home visits to understand their particular needs.

> The information gathered on unmet needs of persons with disabilities and older people was also used to advocate for a more inclusive response by other humanitarian agencies at national level. Team members worked closely with mainstream humanitarian organizations to sensitize them on disability issues and equip them with simple tools and approaches to include persons with disability and older people in their programmes.
>
> One of the main lessons from the ageing and disability focal points initiative is to involve persons with disabilities and older people in emergency preparedness initiatives. This can ensure that mainstream humanitarian agencies already have the knowledge and mechanisms to reach these groups when disasters strike, and persons with disabilities and older people, as well as their representative organizations, are equipped with the necessary capacity to actively engage in the response effort from the outset.

Finding a way to bridge the gap – ensuring that mainstream humanitarian organizations are age and disability competent on the one hand, and local disability- or age-focused agencies are adequately resourced and supported to inform and guide the response on the other – will mean departing from currently accepted norms in the humanitarian sector. And, as others have already articulated, it likely necessitates a radical overhaul of the institutions, the power dynamics between them, the way that success is articulated and measured, and the flow of resources to and between responding organizations (ODI, 2016; ALNAP, 2015b; Development Initiatives, 2017b).

4.6 In the loop: conclusions and recommendations

Some progress has been made on including older people and persons with disabilities in humanitarian response. The SDGs have been key in moving the development agenda forward to leave no one behind, and the humanitarian community continues to look for ways to respond to people most in need. A proliferation of guidance, standards and toolkits show that the commitment and the will are there; and, as this chapter has shown, there are many examples of good practice at global and country levels.

The discussion is now not *whether* to make humanitarian action more inclusive, but *how* to make it more inclusive, and how to do so at scale. Humanitarian principles and good practice should automatically lead to the people most at risk and these groups are clearly a priority focus for crisis prevention and response. The various frameworks, commitments and standards that exist are adequate in terms of providing clarity and vision for better inclusion within humanitarian response. But the evidence shows that despite willingness and commitment, those populations are still not being routinely prioritized by mainstream humanitarian agencies. Good practice is ad hoc, not systematic. Too much is expected of specialist institutions and organizations – those focusing on age, disability, gender or

other issues – and not enough is being done by others. As a consequence, older people, persons with disabilities and other potentially vulnerable groups remain at risk of being left out of the loop, and left behind by humanitarian response.

Moreover, focusing on specific aspects of people and groups separately – such as disability, age or gender – fails to consider the multiple and interlinked vulnerabilities, needs and capacities of people affected by crises. Overcoming this mindset is further entrenched by the architecture of the humanitarian sector that navigates by sector (e.g. health) or by entire population groups (e.g. refugees). Divisions between population groups can be further entrenched by a lack of collaboration between age- and disability-specific organizations (HelpAge International, 2018), as well as between specialist agencies focusing on other target groups or cross-cutting issues.

From a practical point of view, the following key recommendations can help push the agenda forward and go the last mile towards better inclusion of older people, persons with disabilities and others who may be left out of the loop in humanitarian action.

4.6.1   Improved understanding: data, information and research

— **Humanitarian actors – international, national and local – should radically improve the data on older people and persons with disabilities to better identify, understand and account for specific needs in humanitarian programming.** This includes not only data collection and analysis but also overcoming the continued risks and resistance to greater *sharing* of data. Lack of data is not the only reason why older people and persons with disabilities are frequently excluded from humanitarian action – but it is a clear contributing factor. People need to be visible and counted for humanitarians to understand their situations and be held accountable for responding appropriately to their needs and capacities.

— Data is particularly lacking on persons with disabilities, and the granularity of both age- and disability-related data falls short. For example, distinguishing between different age groups within the broader heading of 'old age', and identifying different types and severity of disability, as well as upper age limits on humanitarian assessments and surveys which thereafter exclude older people from participating in certain initiatives, including livelihood programmes.

— **Language and literacy levels of everyone** in need should be systematically and routinely captured and questions on language and **communication needs should be included in multi-sector needs assessments**, as proposed by the Inter-Agency Standing Committee (IASC) Task Team on Accountability to Affected People and Protection from Sexual Exploitation and Abuse, and Translators without Borders, in early 2018. Factoring language and other potential barriers to communication into the design and resourcing of participation and accountability mechanisms will help ensure minority language speakers and less literate people are not excluded. Gender is often a key factor influencing language and literacy skills and should not be forgotten.

— Where publishing language data entails risk for the people concerned, safe ways of managing that data and making available only what is needed to inform strategy need to be found.

4.6.2 Inclusive responses: partnerships, staffing and communications

— **Efforts to increase inclusive humanitarian action should be undertaken with the direct participation of older people, persons with disabilities and other marginalized groups wherever possible.** This requires stronger alliances between local DPOs/OPOs, governments and mainstream humanitarian organizations as well as ways of working that genuinely allow for the voices and skills of older people and persons with disabilities, and other potentially marginalized groups (such as minority linguistic groups, migrants and women) to shape humanitarian responses. This begins with reviewing the staffing of humanitarian organizations and considering the extent to which they are age- and disability-inclusive, and how in turn this affects their ability to reach out to potentially marginalized groups.

— Humanitarian responders need to be aware that some people may be stigmatized and hidden from view. As the work of the Kenya Red Cross Society to overcome prejudice towards persons with disabilities shows, sustained community engagement can help better reach people who have been left behind owing to stigma while helping to shift perceptions and attitudes.

— As illustrated by the example of BBC Media Action, Internews and Translators without Borders in the refugee response in Bangladesh, **a collective approach to multilingual communication with affected populations can help make humanitarian action more accountable to, and effective for, people most often left out of the loop.** This would help ensure that key resources are geared to the needs of minority language speakers, non-literate people and people with less access to technology.

— **Programme budgets should include provisions for meeting the specific needs of marginalized groups – and this should include tailored communications.**

4.6.3 Focused investments: supporting local action and participation

— **Donors and sub-granting international organizations should enable and forge better links with local-level action, led by groups that may otherwise be left out of the loop.** The research for this chapter found that some of the best and most effective action with and on behalf of persons with disabilities is happening at the local level, often initiated and led directly by persons with disabilities.

— **Donors should help to raise the bar on inclusion, pushing organizations receiving their funding to do more to include older people, persons with disabilities and other groups at risk of being left out of the loop in their programmes.** As investments in

better quality data, capacity building and inclusive and participatory programming are potentially high, donors can also make a valuable contribution by providing humanitarian organizations with the space, time and resources to interact with people who are affected by crises and develop demand-driven responses that genuinely respond to their needs.

Sulawesi, Indonesia, 2018.

Sahoriya, 73, survived the earthquake and tsunami which struck Sulaweisi. Crises can have a disproportionate impact on older people: 4 people died in the village of Loli Saluran and all were older people.

©Benjamin Suomela/Finnish Red Cross

South Sudan, 2013

A 'returnee' at a camp for those who had fled conflict in Sudan. This community has received vital resources from the South Sudan Red Cross Society, however many challenges remain.

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