Disability inclusion and disaster risk reduction

Overcoming barriers to progress

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Key messages

- Although the rights and needs of people with disabilities in disasters are increasingly being addressed through policies, standards and guidelines, much more needs to be done to remove the barriers to their inclusion in disaster risk reduction (DRR) and response.

- Effective institutions with supportive attitudes, structures and systems, backed up by good evidence, are key to meaningful disability inclusion. Human rights-based approaches have the potential to lead to a major shift in institutional policy and practice towards disability.

- Disability advocates and disabled people's organisations can play a significant role in disaster policy, planning and interventions, but formal disaster agencies tend to have limited interaction or collaboration with them.

- People with disabilities are not a homogenous group. Disability intersects with a range of other individual, social, economic and cultural factors, leading to differing vulnerabilities and inequalities. Disability inclusion cannot be achieved without challenging the societal and institutional discrimination, marginalisation and exploitation experienced by people with disabilities in disasters and at other times.

Introduction

Disasters have a disproportionate impact on people with disabilities, who are at higher risk of death, injury and loss of property. They are less likely to receive timely warnings before an event; they find evacuation routes and public shelters difficult to access or even inaccessible; appropriate care and shelter facilities are often lacking; and they are overlooked in relief and recovery assistance. People with disabilities (physical, psychosocial and cognitive) are also more likely to be poor or unemployed, socially marginalised, excluded from decision-making processes and living in hazardous locations in poor housing and with inadequate infrastructure and limited access to basic services. Disasters can be a significant cause of permanent injuries and impairments, and can exacerbate pre-existing conditions through the loss of equipment or medication.

Disability has become more prominent in the disaster policy agenda since the UN Convention on the Rights of Persons with Disabilities (UNCRPD) entered into force in 2008. The Convention requires states to take 'all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk', including conflict, humanitarian emergencies and natural hazard events (UNCRPD, 2006: Article 11; Schulze, 2009). It has been signed by more than 160 states and regional organisations, and is influencing national disaster legislation in many countries. Likewise, the Sendai Framework for Disaster Risk Reduction, adopted by UN member states in 2015, emphasises the importance of inclusion and accessibility, and recognises the need for the involvement of people with disabilities and their organisations in the design and implementation of disaster risk reduction (DRR) policies (Stough and Kang, 2015). The 2016 World Humanitarian Summit endorsed a Charter on Inclusion of Persons with Disabilities in Humanitarian Action, which pledged to place people with disabilities at the centre of humanitarian response, and to ensure they receive protection and assistance without discrimination.[1] Other global and regional policy instruments have also addressed the rights and needs of people with disabilities in disasters.[2] The Sphere standards have included a commitment to disability inclusion as a cross-cutting issue since 2011. This was taken further in the *Minimum standards for age and disability inclusion in humanitarian action*, piloted in 2015, which set out a large number of general and sector-specific standards (Njelesani et al., 2012; ADCAP, 2015).

These policy changes have encouraged the development of standards and guidance that recognise the heightened vulnerability to disasters of people with disabilities, and the need to account for and include them in disaster risk management. A number of guidelines and manuals on disability-inclusive disaster management have been issued by international organisations, government agencies, disabled people's organisations and disability-focused national and international NGOs.[3] Humanitarian inclusion standards for older people and people with disabilities have been published by the Age and Disability Capacity Programme (ADCAP, 2018), and the Inter-Agency Standing Committee (IASC), the primary mechanism for the coordination of humanitarian assistance involving key UN and non-UN humanitarian partners, is piloting guidelines on the inclusion of people with disabilities in humanitarian action, to be launched at the end of 2018.[4]

These are significant and positive steps, but how far and how quickly is the ideal of inclusion being translated into humanitarian and DRR practice, and how much progress is being made towards removing the physical, social and cultural barriers to inclusion? There are signs of good practice in DRR and humanitarian programming, for example inclusive hospital preparedness plans, targeted cash transfers and training and sensitisation for staff on working with people with disabilities. Overall, though, disability remains inadequately integrated into relief and disaster planning, with every new disaster providing further examples of people with disabilities being overlooked or marginalised, and unthinking and inappropriate interventions. Manifold implementation, funding, monitoring and outreach gaps limit impact at the local level, and there is scant evidence of effective strategies to implement or monitor plans for effective inclusion (Kett and Twigg, 2007; Davis et al., 2013; Kett et al., 2018).

Disaster agencies and actors need a better understanding of the contexts and challenges they face in seeking to achieve transformative change. This briefing note identifies five key challenges that need to be addressed in order to promote disability inclusion

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1 http://humanitariandisabilitycharter.org/.

2 For example, the Verona Charter on the Rescue of Persons with Disabilities in Case of Disasters (2007) (www.eena.org/ressource/static/files/Verona%20Charter%20approved.pdf); the Incheon Strategy to 'Make the Right Real' for Persons with Disabilities in Asia and the Pacific (2012) (www.unescap.org/resources/incheon-strategy-%E2%80%9Cmake-right-real%E2%80%9D-persons-disabilities-asia-and-pacific); and the Dhaka Declaration on Disability and Disaster Risk Management (2015) (www.preventionweb.net/english/professional/policies/v.php?id=47093).

3 For example, Alexander et al. (2015); O'Meara (2012); WHO (2013); NOD (2009); Glette et al. (2015).

4 https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action.

in DRR and humanitarian action, relating to evidence and data, contextual understanding, institutions and programmes, representation and discrimination. It highlights the importance of rights-based approaches, together with improved standards and indicators, in overcoming these challenges.

Evidence and data

Evidence and research from disasters and crises in different contexts, including earthquakes in Japan in 1994 and 2011, the Indian Ocean tsunami in 2004 and Hurricane Katrina in 2005, have raised awareness and encouraged efforts to improve practice around disability (Alexander et al., 2012; Hemingway and Priestley, 2006; Tatsuki, 2012; Kett et al., 2005). Nevertheless, much better data is needed on disability in disaster contexts, particularly on the impacts and outcomes for people with disabilities, the nature and extent of impairments resulting from injuries sustained in disasters, and the longer-term health and other consequences of disaster injuries for functioning and wellbeing.

Although policy statements recognise the value of disability-disaggregated data for identifying people and needs, the shortage and inaccuracy of pre-existing data on the number and location of people with disabilities, and the range of their disabilities, undermines disaster planning and response efforts (Smith et al., 2012). Official data sources often underestimate the number of people with disabilities, and disaster planners and responders often believe that few are present in their communities. As a result, people with disabilities are overlooked in preparedness and contingency planning and miss out on relief distributions, or they are treated as a single group rather than in line with their different needs and capabilities (for example, after the 2004 tsunami: Kett et al., 2005; IDRM, 2005). Special needs registries, providing information on the location and requirements of people with disabilities, can play a vital role in targeting support, as, for example, in rescue and rehabilitation following the 2010 floods in Pakistan (Smith et al., 2017). Agencies must be willing to supply the financial, technical and human resources needed to maintain accurate and up-to-date information. More methodological consistency in data collection is also required (using the 'Washington Group questions', for example),[5] together with appropriate tools and staff training in disability inclusion and awareness.

Specific rapid needs assessments, supplying basic information on the level of access to services, challenges and priority needs, are essential in order to ensure inclusive emergency interventions. In practice, rapid needs assessments in disasters rarely include people with disabilities, or have questions on disability. Even the best tools can be applied inappropriately: for example, it has been shown that vulnerability and capacity assessments often overlook disability (Twigg, 2014). Some methods for gathering field data, such as transect walks and focus group discussions, may be inaccessible to people with disabilities without appropriate support, and risk analyses generally do not account for the social exclusion of people with disabilities, which may be exacerbated during emergencies. Few disaster management or relief organisations include disability adequately in their monitoring, evaluations or reviews of their interventions, and very little is known about the long-term recovery trajectories of people with disabilities. Agencies also make very little use of the knowledge and information held by disabled people's organisations and people with disabilities themselves (Hemingway and Priestley, 2006; Stough et al., 2010; Stough et al., 2016).

New information and communications technologies, such as online mapping, crowdsourcing and social networking tools, have the potential to engage, support and protect people with disabilities during disasters (for example through warning dissemination, damage assessment, locating resources for relief and recovery, connecting people with disabilities with service providers and suppliers and providing channels for communication and accountability). In the Indian Ocean tsunami, for instance, disabled people's organisations used internet searches, websites and mailing lists to identify relief needs and sources of emergency assistance (Stough and Kang, 2015; Hemingway and Priestley, 2006). Such technologies must be accessible to people with disabilities, otherwise those without such access will be marginalised further (Raja, 2016).

Context

Disabled people's vulnerability in disasters is the result of the interaction between the impairment, the physical environment and social and institutional structures and attitudes. This is generally understood in policy statements, but in practice disaster organisations and their staff continue to focus on helping individuals with impairments adjust to their situation, rather than altering the environment to accommodate their needs (Hemingway and Priestley, 2006).

People with disabilities are often portrayed as helpless in the face of disasters. Agency assessments tend to focus on their vulnerabilities and overlook their knowledge, skills and resources for dealing with hazards and disasters. All disaster-prone individuals,

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families and communities develop coping mechanisms, drawing on their own skills, knowledge and social and institutional networks. People with disabilities are no exception (Stough et al., 2017). In fact, their experience of overcoming barriers and negotiating difficult physical environments in daily life may make them better equipped to cope psychologically in a crisis than non-disabled counterparts (Rahimi, 1993; Abbott and Porter, 2013; Alexander et al., 2012; Lord et al., 2016).

People with disabilities are not a homogenous group: individuals have varying degrees of resilience to hazard events and other shocks, which are not due simply to impairment. Disability results from the interactions between people with impairments and the social, attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (UNCRPD, 2006). It intersects with a range of other individual, social, economic and cultural factors, such as age, gender, ethnicity, religion and poverty. Societal norms that perpetuate existing hierarchies and inequalities lead to different or unequal outcomes for people with disabilities. For example, women disabled by the 2005 earthquake in Pakistan were more isolated socially, emotionally and financially than similarly disabled men (Irshad et al., 2012). These intersections between social identities must be understood and addressed. Data collection, analysis and interpretation should take these layers of complexity into account, and pay more attention to distinct groups of people with disabilities, for example children, whose particular physical, psychological and educational vulnerabilities tend to be overlooked in disaster planning (Peek and Stough, 2010; Ronoh et al., 2015).

Institutions and programmes

Translating the language of disability inclusion into meaningful action on the ground requires supportive attitudes, structures and systems within organisations involved in DRR. One useful step forward would be to measure or benchmark the extent to which disaster-related initiatives are disability-inclusive, and what effect they have on the resilience and wellbeing of people with disabilities. This has been advocated by the Global Facility for Disaster Reduction and Recovery (GFDRR) for the World Bank's disaster risk management portfolio, and could usefully be taken up by other agencies (Guernsey and Scherrer, 2017).

Implementing organisations often have little in-house expertise in disability. In many organisations, advocacy for and uptake of inclusive approaches rely heavily on the influence of individuals with a personal interest in this area. Mechanisms for promoting disability coordination across sectors and institutions, such as committees or focal points, often have limited impact

locally, and many actors, particularly first responders, feel they do not have the training or tools to respond appropriately to the specific needs of people with disabilities. While people with disabilities may require individual disaster assistance that is specifically tailored to their needs, and some services may need specialised agencies, there is a widespread misconception that everyone with disabilities requires specific and complex services that cannot be implemented by humanitarian and disaster actors.

Lack of funding for programmes focused on disability, and for mainstreaming disability into wider programming, is a major constraint on disaster institutions wishing to support people with disabilities, and can also lead to disability issues being sidelined or ignored (Kett et al., 2018). The benefits of more inclusive programming extend to all members of society. For example, the application of accessibility standards and universal design to early warning systems increases those systems' ability to warn people with and without disabilities about impending threats. Health services can be overwhelmed by disasters and unable to give adequate support to large numbers of people with disabilities and newly injured people, as in Gujarat after the 2001 earthquake and Haiti in 2010 (Chatterjee, 2002; Tataryn and Blanchet, 2012; Danquah et al., 2015). Other essential services that people with disabilities normally draw on for support, such as social security systems, also need to have the capacity to respond to severe shocks quickly and effectively (Holmes et al., 2018).

In practice, disaster responders have to balance the need to provide standardised assistance to large numbers of people against more targeted individual coverage. Both approaches can result in people with disabilities being overlooked: mainstreaming of disabled adults and children into policies and programming can result in them becoming invisible within these programmes, while targeting requires resources and capacity that may not be available in a crisis.

Representation

Listening to people with disabilities and learning about their experiences is essential. Disability advocates have played a significant role in shaping international disaster management agendas, notably the Sendai Framework. Participation in decision-making is considered a key issue by people with disabilities, and by their organisations (Stough and Kang, 2015; Wisner, 2002; Handicap International, 2015).

Lack of coordination or engagement between formal actors and people with disabilities and their representative organisations is widely reported in many countries and contexts, even in countries with progressive disability legislation and relatively high

levels of awareness of disability issues, such as the United States (NCD, 2006; Fox et al., 2007; Lord et al., 2016). People with disabilities are often excluded from emergency planning and programming by their governments, particularly at local levels, and there appears to be limited political will in favour of inclusion (Wisner, 2002). International institutions such as UNISDR and the World Bank could play a convening role to bring together people with disabilities, disabled people's organisations and DRR and humanitarian experts for knowledge-sharing, networking and agenda-setting. So too can national governments, as in the case of the two international conferences on disability and disaster risk management in Dhaka in 2015 and 2018 organised by the government of Bangladesh.[6]

Disabled people's organisations have specific disability expertise that is not readily available within mainstream disaster response, and access to informal networks of support and communication (Wisner, 2002; Hemingway and Priestley, 2006). However, interaction and collaboration between these organisations and other disaster actors is generally weak, and it is rare for disability-focused organisations and people with disabilities to take leadership roles in DRR and disaster response. The challenges of inclusion and partnership need to be addressed well before the disaster or emergency occurs. This involves increasing the representation of people with disabilities on decision-making bodies at all levels, and forging partnerships with disabled people's organisations.

Discrimination

Disability inclusion cannot be achieved without challenging the societal discrimination, marginalisation and exploitation often experienced by people with disabilities, which restricts their access to education, health, food, rehabilitation services, employment and other forms of social protection (Alexander et al., 2012; Kett and Twigg, 2007). This discrimination takes many forms, deliberate or unconscious, organisational as well as social. It is founded on deep-rooted cultural assumptions, social structures and economic inequalities.

In disasters, people with disabilities face many obstacles in accessing assistance and protection. For example, warning and evacuation plans may overlook the needs of people whose visibility, hearing or mobility is impaired, and emergency shelters and sanitation facilities often fail to take physical accessibility into account. Relief distributions often effectively exclude people with disabilities: distribution points may be distant or inaccessible, and people with disabilities may not be able to queue for long periods for relief goods or carry them away. Information about distribution times and locations may not be communicated in ways that can be understood by people with hearing, visual or intellectual impairments. Specific dietary needs may not be met by standard food distributions, and appropriate medication and therapeutic support are often unavailable (Alexander et al., 2012; Hemingway and Priestley, 2006; Kett and Twigg, 2007; Twigg et al., 2011; Handicap International, 2015). Pre-disaster discriminatory practices and exclusion continue into the recovery period, with the result that physical, social and institutional barriers are rebuilt (Zayas et al., 2017).

People with disabilities are among the most neglected during evacuation, displacement and return, with particularly restricted access to social networks and other sources of support. Social stigma and fear may make them reluctant to identify themselves as disabled (Kett et al., 2005; Kett and Twigg, 2007; FMR, 2010). People with impairments related to mental health or cognitive or developmental support needs are often particularly vulnerable to discrimination. There are instances of them being turned away from emergency shelters, and relief agencies are rarely able to provide the specialist assistance they need (Davis et al., 2013; Stough, 2015; Twigg et al., 2011). There is clearly a need to challenge social norms that marginalise people with disabilities, even though doing so can be problematic and contentious (Le Masson, 2018).

Conclusion

Overcoming the barriers to inclusion identified here is clearly a major challenge, but there are indications that progress can be made through the implementation of rights-based approaches and by developing and applying indicators of inclusion in humanitarian and DRR interventions. These are basic levers of change, providing impetus for a wide range of positive steps in policy and practice.

Inequality and exclusion of people with disabilities, or violation of their dignity (for example through violence or abuse), are issues of human rights, social justice and entitlement. For many years, rights-based approaches have been advocated as having the potential to lead to a paradigm shift in institutional policy and practice towards disability. A human rights-based approach to disability sees people with disabilities as people with inherent rights, who are capable of claiming those rights and making decisions, as well as being active members of society. The rights set out in the UNCRPD, and echoed in subsequent policy instruments, legislation, standards and guidelines, place a number of responsibilities upon

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6   http://dkconf18.modmr.gov.bd/.

duty-bearers: to ensure application of the principles of dignity, equality and non-discrimination to people with disabilities; to promote and protect their inclusion and safety; to sensitise international and national agency staff, and national and local authorities, on the rights, protection and safety of people with disabilities; and to ensure that people with disabilities affected by crises know their rights and entitlements, have access to information and participate in decisions that affect them on an equal basis with others. A rights-based approach also addresses programme planning and implementation (Njelesani et al., 2012; ADCAP, 2018).

Measuring the progressive realisation of the inclusion and rights of people with disabilities requires clear and measurable standards and indicators, particularly in countries where effective anti-discrimination legislation is absent. Goal 10 of the 2030 Agenda for Sustainable Development calls for reducing inequalities in income, as well as those based on sex, age, disability, race, class, ethnicity, religion and opportunity. However, UN member states that have committed to the 2030 Agenda have commented on the lack of disaggregated data on vulnerable groups such as migrants, refugees, older people, people with disabilities, minorities and indigenous peoples (UN, 2016). A similar concern about the lack of readily available, reliable and comparable data was expressed at the 2017 mid-term review of the inter-governmental Incheon Strategy to improve the quality of life and the fulfilment of rights of people with disabilities in Asia and the Pacific (UNESCAP, 2017).

ALNAP's 2010 *State of the humanitarian system* review found that '[t]here is little if any consideration of issues relating to disability in the recent literature or in the evaluations reviewed, and it seems that this is another mainstreaming challenge struggling to receive sufficient attention' (ALNAP, 2010: 47). More clarity is needed about appropriate indicators to demonstrate what successful inclusion and increased resilience look like. There seems to be little agreement about indicators for disability-inclusive DRR programmes, and there is little evidence of targets being applied on the ground.

Even so, there have been signs of progress. The Incheon Strategy set out key indicators for strengthening disability-inclusive DRR planning and support to people with disabilities in disasters, together with basic guidance on data collection (UNESCAP, 2014). Under the Sendai Framework, UNISDR has a mandate to develop minimum standards and metadata for disaster-related data, statistics and analysis. Its 2017 technical guidance on collection of monitoring data recommends disaggregation by hazard, geography (administrative unit), sex, age, disability and income for two specific data categories, deaths and missing persons (Target A) and people directly affected (Target B): this refers to pre-event disability rather than those who develop disabilities during or as a consequence of the event (UNISDR, 2017). These formal initiatives should be complemented by other monitoring data, qualitative as well as quantitative, generated on the ground by disabled people's organisations and people with disabilities themselves.

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**Evidence.
Ideas.
Change.**