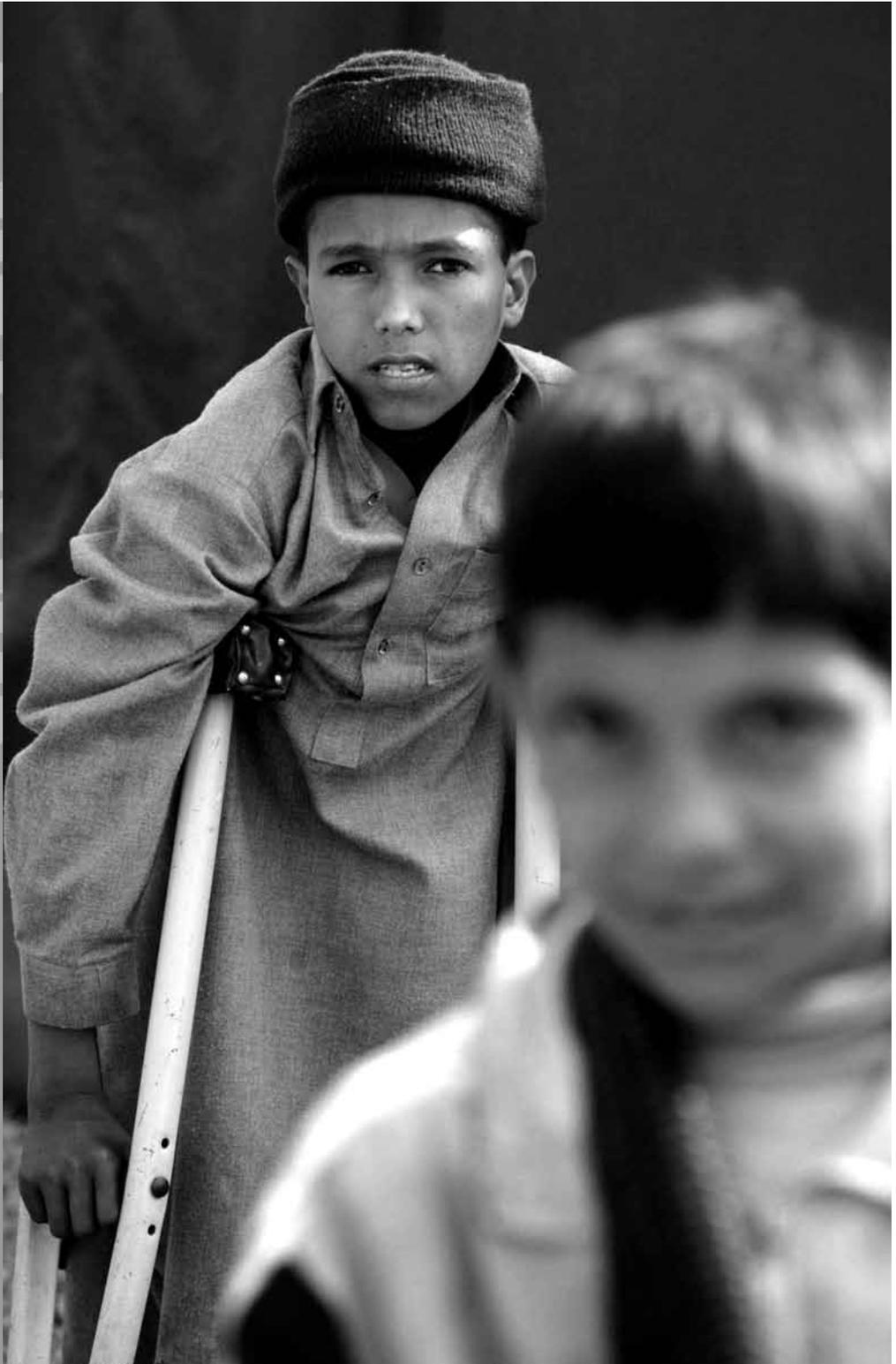


CHAPTER 4



Disability and disasters: towards an inclusive approach

According to the World Health Organization (WHO), there are over 600 million persons with disabilities worldwide – between 7 and 10 per cent of the global population – 80 per cent of whom live in developing countries. Their number is increasing through population growth, greater longevity and advances in medical technology.

Disability and poverty are linked in a vicious cycle. Across the world, persons with disabilities (see Note) are disproportionately poor because of barriers, discrimination and exclusion from opportunities to escape the unending poverty that they face. Marginalized by laws, customs, practices and attitudes, in addition to having a difficult physical environment, they are excluded from educational and livelihood opportunities. Poor people have limited access to health care, shelter, food, education and employment, and are more likely to work in hazardous conditions – all factors that increase the risk of illness, injury and impairment.

Persons with disabilities are doubly vulnerable to disasters, both on account of impairments and poverty; yet they are often ignored or excluded at all levels of disaster preparedness, mitigation and intervention. They are particularly at risk of marginalization and discrimination in such situations due to exclusionary policies and practices by communities and the agencies involved in providing humanitarian aid and intervention.

This chapter will explore why they have been excluded from these processes; the mechanisms now in place to redress this, including the recent UN Convention on the Rights of Persons with Disabilities; and what they are doing to make themselves more resilient to disasters.

Context

There is no single agreed definition of disability, while there are many local understandings of who is disabled and what disability constitutes. There is also little internationally comparable information. Higher-income countries tend to demonstrate higher rates of people registered as disabled, which seems to be in part because of broader definitions of what disability is and the availability of welfare structures and resources.

Photo opposite page:
Many people suffered fractures during the earthquake which struck Pakistan in October 2005. In the field hospital at Abbottabad, provided by the Norwegian Red Cross, children learnt to use crutches to walk after becoming disabled.

Olav A. Saltbones/
Norwegian Red Cross

The UN Convention on the Rights of Persons with Disabilities does not define disability. However, it notes that:

“Disability is an evolving concept and results from the interaction between a person’s impairment and obstacles such as physical barriers and prevailing attitudes that prevent their participation in society. The more obstacles there are, the more disabled a person becomes. Persons with disabilities have long-term physical, mental, intellectual, or sensory impairments such as blindness, deafness, impaired mobility, and developmental impairments. Some people may have more than one form of disability and many, if not most people, will acquire a disability at some time in their life due to physical injury, disease or ageing.”

The ‘social model’ perspective currently forms the basis of many disability policies and practices. This model focuses on discrimination and exclusion rather than impairments – and provides a tool to analyse the barriers to persons with disabilities that prevent full participation, inclusion and access to their rights. These barriers can be social, economic, physical, institutional, attitudinal and cultural. One or all of them may present themselves to persons with disabilities across the world, and can result in poverty, discrimination and social exclusion. Disability is therefore best understood as a multidimensional concept.

Disasters create disability

Disasters and emergencies can leave a huge legacy of impairment and injury, although the actual injury rate and numbers depend on the context and type of disaster. For example, an earthquake in Armenia in 1988 killed 25,000 people but injured 130,000 of whom 14,000 were hospitalized. It is estimated that for every child killed as a result of violent conflict, three are injured and permanently impaired. Inevitably, there are difficulties obtaining such data in the immediate aftermath of a disaster or conflict, and many organizations do not collect disability-related data in the immediate needs assessments. Following an initial assessment of the situation in post-conflict southern Sudan, Handicap International and its partners in the field estimated that over 11 per cent of the population were disabled, but that this number only actually reflected those visible to the team.

While those injured as a result of the disaster or conflict may be very visible, it is important to remember that many other people living in the affected areas may already be disabled, and may then become further marginalized and excluded on the basis of their disability in the aftermath.

To avoid such exclusion following a disaster or emergency, it may be helpful to consider persons with disabilities in different groups, such as:

- those with an injury that may be at risk of developing into an impairment (for example, injuries such as bone fractures not properly treated or followed up after discharge)
- people whose injuries result in (permanent) impairment (for example, spinal cord injuries, amputations etc.)
- people who were already disabled prior to the emergency or disaster
- people with chronic diseases (including HIV, epilepsy, diabetes etc., which can all deteriorate without medication)

Despite the obvious direct correlation between disability, disasters and conflicts through injuries or accidents, there are also more indirect effects such as inadequate health care, poverty, and malnutrition, loss of support structures and change of environment. If the health care system is disrupted, as it often is in such situations, and relief organizations have limited capacity to follow up or include people with chronic illnesses, then there is a risk of further disability. The loss of family members, homes and livelihoods in the aftermath of a disaster means that recovery may be slow. Families may have to adapt to new structures and seek alternative means of income. In some instances, those who are seen to be ‘victims’ of a disaster or emergency may receive the most input and services.

Policy and discrimination

In 1991, as a contribution to the UN Decade of Disabled Persons, the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules) were adopted, based on existing international human rights legislation. Yet in 2006, a global survey by the UN Special Rapporteur on Disability found that persons with disabilities still faced discrimination in many areas of life. For example, even if they were employed, they were not always entitled to the same privileges as persons without disabilities. Children with disabilities still faced many barriers in accessing education across the world – in both developing and developed countries. These two factors alone contribute significantly to ongoing economic marginalization and, as the report notes, “...explain why persons with disabilities are the poorest of the poor”. This is compounded by a lack of government action to ensure income maintenance and support.

The survey also drew attention to disasters and emergencies, in particular to ways in which persons with disabilities have been largely overlooked in relief programmes. To this end, it suggested that states, in conjunction with relevant UN agencies, should develop inclusive policies and guidelines for persons with disabilities in emergency situations.

The Standard Rules were a precursor to the UN Convention on the Rights of Persons with Disabilities, which was adopted by the General Assembly of the United Nations

in December 2006. The formal ratification process began on 31 March 2007 in New York. The convention comprises 50 articles, covering a wide range of issues including education, health, international cooperation, equality and non-discrimination. Particularly relevant to this discussion are Article 32, International cooperation, and Article 11, Situations of risk and humanitarian emergencies (see Box 4.1).

Discrimination in emergencies

Persons with disabilities encounter many problems before, during and after disasters and emergencies, which are not necessarily due solely to their impairment but also to the inadequacy of disaster risk reduction and response systems in meeting their particular needs. In addition, these specific needs may vary according to the time of the intervention: pre (mitigation), during (immediate) and after (intermediate and long-term). In general, the needs of persons with disabilities are often overlooked by disaster planners and they have little or no input into disaster risk reduction planning.

Box 4.1 Articles 32 and 11 of the UN Convention on the Rights of Persons with Disabilities

Article 32: International cooperation

1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:

- Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;
- Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;
- Facilitating cooperation in research and access to scientific and technical knowledge;

d. Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.

Article 11: Situations of risk and humanitarian emergencies

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters. ■

An example of this comes from Bangladesh, a low-income country frequently affected by disasters and flooding, and with an estimated 12 million persons with disabilities (see Box 4.2). One recent survey of them in the cyclone-prone coastal belt found clear differentials in the distribution of relief and rehabilitation aid between families that had members with disabilities and the rest of the community. Only 3 per cent of the sample had received any targeted support for persons with disabilities from flood relief and rehabilitation programmes. The survey found that many persons with disabilities were widely excluded on the grounds of inaccessible shelters and food distribution mechanisms. The survey also found that even some of the materials widely used in the reconstruction phase, such as corrugated iron sheets for roofing, had the potential themselves to cause serious injury and even impairment to people repeatedly affected by disasters.

However, these problems are not confined to any one country or region. The general problem of exclusion has been demonstrated by the experience of major events such as Hurricane Katrina, and by research in such diverse locations as California, New Zealand and South Asia, as well as by extensive anecdotal evidence.

According to the *IASC Operational Guidelines on Human Rights and Natural Disasters*, this exclusion is mainly a result of “inappropriate policies or simple neglect”. To this, we would add discrimination. As the guidelines note, the longer the situation of displacement continues, as a result of a disaster, the greater the risk of discrimination and human rights violations. There is evidence that persons with disabilities are particularly at risk of marginalization and discrimination in such situations due to exclusionary policies and practices by communities and the agencies involved in providing humanitarian aid and intervention. Persons with disabilities, especially women and children, are particularly vulnerable to violence, exploitation and sexual abuse in such situations. Anyone affected by disasters or conflict is more vulnerable to mental health and psychological problems – which may result in misunderstandings and further isolation and social exclusion for families and communities.

The *IASC Operational Guidelines* specifically mentions persons with disabilities in a number of areas:

- camp security (location and layout of camps and settlements)
- safe and non-discriminatory access to available humanitarian assistance
- available, acceptable and adaptable provision of goods and services without discrimination
- inclusion in long-term planning of resettlement and reconstruction
- inclusion in livelihood measures, such as microcredit opportunities
- appropriate mechanisms for feedback regarding relief, recovery and reconstruction responses

Box 4.2 Bangladesh: discrimination during floods

Following an accident about eight months back, my husband, a truck driver, lost his right hand, two lower limbs, and became paralysed from below his neck. We haven't yet learnt how to cope with this loss. We have never seen floods in our village before. There were no boats around when the flood waters rushed in. We sat on the roof for three days. Then our house was washed away, so we had to move here. But moving such a big man is difficult. The toilets are also too far away. Now when he defecates in bed, the other families suffer from the stench, and so they have tried to throw us out. It seems that the authorities here are also thinking along the same lines.

Setara Begum, 45, in a flood shelter at Jessore, 2001

Bangladesh is one of the most flood-prone countries in the world. Essentially, it is a flood plain criss-crossed by 230 rivers. When the rivers flood, so does Bangladesh. In addition, frequent cyclones can drive millions of tonnes of sea water over coastal areas. For a country with about 1,000 people per square kilometre, this can spell catastrophe – particularly for people in rural areas.

But of all Bangladeshis, those with disabilities – who constitute 6 per cent of the population – suffer by far the most during recurrent floods. As well as facing challenges of mobility, sight, hearing, speaking, sensing or rationalizing, they face additional barriers of discrimination from the non-disabled community in their day-to-day lives – discrimination which gets worse during disaster.

As part of their flood response, only a handful of organizations operate flood shelters. The rest generally organize relief programmes. Depending on the budget and human resources available, they vary from large numbers of relief teams with comprehensive aid packages to very small responses. Whatever the scale, in most cases persons with disabilities are usually left out of the effort. This is not done intentionally but because relief teams do not know where to find them – and because relief efforts tend to focus on the most accessible areas.

Even if families can evacuate with their disabled members in time to find relief distribution points, they find it almost impossible to stand in queues for the long hours needed to access aid. So here, too, they do not get their fair share. Mothers of children with disabilities and wives of disabled husbands are torn between the moral duty to remain by the side of their loved ones or standing in long queues to fetch the scant relief that is available. They may send their other children to fetch aid, but a child usually gets given a far smaller packet which is not enough for the whole family.

Those persons with disabilities who make it to flood shelters face discrimination from other survivors inside. Most shelters are overcrowded, while toilets and water sources are inadequate and inaccessible. Families with mobility-restricted adults find it extremely difficult to pacify the people around them, especially when the paralysed persons have no option but to defecate in their makeshift beds. Since many shelters are in closed warehouses with limited ventilation, other families blame persons with disabilities for adding to the stench and often gang up on them to leave.

Accompanying family members with disabilities to the toilet brings its own risks, as Mariam Bewa, 40, a blind widow in a flood

shelter at Netrokona in 1998, explained: "By the time flood waters became knee-deep in our village, our neighbours began to leave. I didn't know what to do with my two daughters, aged 13 and 15. The only way we earn our living is by begging. But then our tiny hut got washed away. Now at this shelter, in the evenings, if one has to go to the toilet, we all need to go together. But then the relief goods that we get, and our little possessions at the tiny space that we have here, are at risk of being stolen. I wonder how long we will have to cope with this."

Poor lighting after dusk makes the shelters unsafe for single women – especially if the shelters are open-air. And if a family has an intellectually-impaired adult daughter with limited communication skills, they need to deal with additional safety concerns. "My 19-year-old sister is mentally very ill," said Abdul Latif, 25, in a flood shelter at Satkhira in 2001. "She rarely keeps clothes on. It wasn't too much of a trouble at home, as we could always keep her indoors. We live in a joint family, so everyone knew and took care of her collectively. When the flood waters began to rise, our extended families left one by one to better shelters. We stayed at home for four days. But since there was no food and also our house had been flooded, we had to leave. We don't yet know where our close relatives are. Now here out in the public, my mother, my younger brother and I have to keep a constant watch on her for her safety. Every night, we keep awake and watch over her by turns."

Floods can also inflict injuries on people – but greater awareness among relief organizations could reduce the risk. Jahanara Begum, 35, from Bogra village, explains: "After the flood waters receded in 1998, we returned to our homestead. We had to rebuild all the houses in the entire neighbourhood. So the

adults remained busy all day, and didn't mind their children playing in the stagnant waters. My younger son was only about eight then. With the situation improving, all medical help had also left the place. Being illiterate and poor, we didn't know that ear infections could be so bad for the children. Now my son is completely deaf in both ears. There are at least five of his friends who have suffered similar deafness. I wish someone had told us back then that simply cleaning and drying their ears could prevent this problem."

The National Forum of Organizations Working with the Disabled (NFOWD), a network of Bangladeshi non-governmental organizations (NGOs), has consistently raised these concerns with the government and relevant disaster management bodies – as well as issuing guidelines on how to make disaster relief more accessible to persons with disabilities.

In 2000, the government issued special instructions to all district administrators to ensure that persons with disabilities are given priority in evacuation, relief and rehabilitation measures. In 2005, the DER, a disasters and emergency response group of international non-governmental organizations (INGOs) and large national NGOs, hosted workshops looking at disasters and diversity. The DER agreed that, if a response were fully accessible to persons with disabilities, it would become automatically accessible to elderly people, children, pregnant women and people suffering from debilitating illnesses. This has prompted many INGOs to support disability-friendly disaster response plans.

Fortunately, the country has not suffered a major disaster since then. But when floods inevitably inundate the country again, it remains to be seen how effective this planning will prove for persons with disabilities. ■

However, there is still a large gap between policy, guidance and implementation – even in countries with highly-developed disaster policies. In the United States, which is a leader in research and policy in this field, there is still plenty of evidence of exclusion and discrimination. The key question is why, despite the existence of guidelines and standards, persons with disabilities are rarely mainstreamed into disaster and emergency programmes. There are a number of answers that might explain this.

Many agencies and organizations working in the field consider disability to be a specialized subject, requiring technical skill and knowledge, often of a medical nature. This means that when they encounter persons with disabilities in their programmes, they are automatically referred to a specialist agency dealing with disability. These assumptions by agencies and practitioners perpetuate discrimination and exclusion. Within most mainstream humanitarian aid and development organizations, disability has been addressed either as a cross-cutting issue or as part of a vulnerable group.

However, many of the needs of persons with disabilities are exactly the same as everyone else in a disaster or emergency (water, sanitation, shelter, food), but it is how they are provided that matters. Many activities can be undertaken in order to ensure that they and their families access the same benefits and relief as other people. This is not to say that persons with disabilities (and other vulnerable people) may not have particular needs, but to treat them merely as in need of special attention disempowers them and denies them a voice in planning and implementation. It also denies that persons with disabilities have any role to play in disaster relief, disaster risk reduction and recovery. This perpetuates discrimination.

Another exclusionary factor is perceived expense. Constructing accessible buildings, for example, is seen as expensive, even though evidence suggests that it only adds minimal extra cost initially compared to having to alter buildings later on to comply with regulations. Moreover, all of these adaptations benefit the wider community. Time is also a constraint: in many post-disaster situations, there is considerable pressure on governments and donors to complete rebuilding work to allow people to return home.

Other aspects of discrimination in disaster response and recovery are less clear, or less well understood. One of these is the long-term effect of a disaster on a community: how it affects families, income, poverty levels and so on. We need to know much more about the impact on persons with disabilities. There is also very little work on how they reintegrate into communities in the aftermath of a disaster or conflict. However, such situations can also be a catalyst for change and, in a number of countries, have resulted in their forming organizations and lobbying to get disability issues onto the government's agenda; this was certainly the case in

Sierra Leone and Liberia. It is also true that there are few other alternatives for persons with disabilities other than to form self-help groups if there is minimal welfare provision.

Also in the aftermath of an emergency or disaster there is inevitably an influx of organizations and services, so, conversely, persons with disabilities may find themselves receiving better services and care than they did beforehand: for example, rehabilitation services are developed, and assistive devices may be distributed. Despite this, it may be difficult for many people with impairments acquired as a result of the emergency or conflict to adjust to their situation.

Another area that requires consideration is the difference in treatment for those perceived as victims or heroes, and those seen as ordinary persons with disabilities. In many countries, for example in Afghanistan, people seen as martyrs or war heroes are compensated and feted by others in the community, whereas those not injured as a result of war are marginalized and excluded. In Sierra Leone, those who become disabled as a result of disrupted immunization campaigns during violent conflict are not considered for any kind of war-related compensation (see Box 4.3).

Invisibility and identity

One of the biggest factors in the exclusion of persons with disabilities from many humanitarian responses is a paucity of data: as they are not ‘seen’, they are assumed not to be there and are not included. However, evidence from disabled people’s organizations (DPOs) around the world has shown that adults and children with disabilities are often hidden from view, stigmatized by families and communities. They may not be included in national censuses or other registration mechanisms.

For example, in Prakasam District, south of Andhra Pradesh, an area badly affected by the Indian Ocean tsunami in December 2004, the population in 2001 was officially recorded at 3,054,941. According to official data, 35 people died as a result of the tsunami and over 92,000 people were affected. The statistics of the district medical and health office (2005) show there were officially 48,931 persons with disabilities registered (27,437 males and 21,494 females). Leonard Cheshire International staff, who visited the region in the immediate aftermath of the tsunami, observed that “[in] the relief work undertaken by the government and NGOs, persons with disabilities were sidelined and not properly represented”.

But even before the tsunami, persons with disabilities in Prakasam District did not have an adequate support system and even after the enactment of the Indian government’s Persons with Disabilities Act 1995, full inclusion had not happened.

They did not have basic documents such as identity cards, income certificates and ration cards. In addition, the district did not have facilities to provide any of

Box 4.3 War-wounded youth in Liberia and Sierra Leone miss out

During the 1990s, Liberia and Sierra Leone suffered years of violent conflict which resulted in injuries and impairments for large numbers of people. Some of these were deliberately inflicted on people – for example, forced amputations; others were a consequence of fighting, such as war injuries sustained by combatants, including child soldiers. Yet more were a result of years of devastation to previously efficient public health programmes, including immunization campaigns.

In the aftermath of war, how have these persons with disabilities been treated by their respective governments? In many countries, those wounded as a result of fighting are often seen as war heroes. This has not been the case in West Africa. However, in both Sierra Leone and Liberia, those who became impaired as a result of a lack of medical care have received less support than the war-wounded.

In Liberia, many young people with visible impairments are assumed to be former combatants who ‘deserved what they got’. Whatever the cause of their injuries or impairments, very few of the disarmament, demobilization and reintegration (DDR) programmes implemented by the UN and other international organizations in Liberia have made any provision for the large numbers of disabled youth, many of whom are former combatants. Consequently, many disabled youth are stigmatized and neglected – left no option but to beg on the streets of Monrovia, Liberia’s capital.

In 2005, the Liberian government drafted a national youth policy in which disability was highlighted as an area of special concern, in

line with national legislation. However, there were no specific interventions planned for the large numbers of young disabled ex-combatants remaining in Monrovia.

In nearby Sierra Leone, war-wounded and amputees elicit a more sympathetic response – even though the country lacks national disability legislation. In the years after the conflict, many INGOs provided the war-wounded and amputees with housing, skills training and prostheses. However, many of these settlements were built some distance from urban areas, therefore reducing opportunities for integration, schooling, shopping and employment, with subsequent problems of sustainability. In addition, despite promises by the Sierra Leone Truth and Reconciliation Commission, there has been limited reparation for victims. Many people who originally received support have resorted to begging on the streets of the Sierra Leonean capital, Freetown.

In both countries, the large numbers of unemployed and alienated youth are seen as potentially destabilizing forces within society. Discriminatory policies and practices towards young persons with disabilities will not make the situation any less fragile.

It need not be this way. In the Great Lakes region of Africa, including Angola, Burundi and Uganda, the World Bank has initiated a multi-country demobilization and reintegration programme (MDRP) which encompasses specific projects for persons with disabilities, including ex-combatants. The programme seeks to improve understanding of the links between demobilization and reintegration and cross-cutting issues such as disability and gender. ■



The Astrodome in Houston, Texas, provided emergency shelter for thousands of New Orleans residents. Hurricane Katrina left a trail of devastation and many disabled people in a vulnerable situation.

Daniel Cima/
American Red Cross

the support that can facilitate inclusion, such as prosthetic appliances and hearing aids.

In Chennai, the state capital of Tamil Nadu, persons with disabilities who were fortunate enough to be registered with local government agencies did receive some relief following the tsunami, mainly food, clothing and medical support. However, those who were not registered, for example if they had no fixed address, were not given any state support.

But the issue of registration is – like definitions – problematic. Many persons with disabilities are not willing to identify themselves as disabled for fear of becoming labelled and marginalized on this basis.

After the Indian Ocean tsunami, there were many examples of persons with disabilities being unable to escape the waves and drowning. In Sambodhi Residential Home in Galle, Sri Lanka, only 41 of its 102 residents survived; many of the rest were unable to leave their beds or failed to comprehend in time the need to escape. In many countries affected by violent conflict, families that are forced to flee may leave behind children and other family members who are not as mobile. In Sierra Leone, many children with disabilities were abandoned by their families during the conflict.

While shocking, such cases come as no surprise to many in the disability movement. What they demonstrate is that it is not just policies that need changing, but also deep-rooted attitudes and prejudices.

Cultural and attitudinal barriers, such as fear and misunderstanding, can be deeply entrenched and difficult to shift. In some instances, a child with a disability is seen as punishment or retribution (for example, for something the mother did during pregnancy). Children with disabilities are also at risk of abuse and withdrawal of care. This may be within their own families, where they are perceived to be an additional burden, but it can also come from other members of the community. Education, greater gender equality and good antenatal care can help dispel such myths. Women with disabilities are in effect doubly excluded from the mainstream, by disability and gender.

Meeting needs

When it comes to meeting the specific needs of people's disabilities before, during and after disasters, there is a growing amount of guidance and experience to draw on. Most of the documented experiences and research are from developed countries, especially the United States; but despite the vast differences in resources between low-income and high-income countries, the principles and basic approaches are universal.

In theory, disaster risk reduction aims to be inclusive, helping all people at risk and involving a wide range of institutional and community stakeholders. The challenges of inclusion and partnership need to be addressed well before the disaster or emergency occurs – as the executive director of the Center for Independence of the Disabled, New York, said after 9/11: “The time to build relationships is not in the middle of a crisis.” One of the most important outcomes of such exercises should be awareness of the diversity of impairments and people's needs, and hence a recognition that there is no one-size-fits-all approach to supporting them. Adopting a broad and flexible attitude to disability ensures that nobody is left out.

The following paragraphs indicate some specific practical challenges and how they might be overcome.

Physical impairments of various kinds may make standard, domestic disaster risk reduction measures more difficult – such as putting up hurricane shutters, anchoring items inside or outside the home to stop them from falling down in an earthquake or turning into dangerous projectiles in high winds. The tasks of cleaning up and repairing homes after a disaster are, similarly, more challenging.

Improvements to the physical environment give greater protection and make evacuation easier. Homes, workplaces, escape routes and emergency facilities can be

designed or redesigned with the needs of persons with disabilities in mind. In the home, for example, furniture and other possessions can be arranged and secured in such a way that they will not obstruct movement in an emergency. In public buildings and workplaces, the evacuation can be facilitated through the provision of ramps, handrails or pathway marking systems and other special signing, as well as the widening of passageways and staircases. Buildings and sites should be developed and improved according to the principle of universal design: an approach to the design of all products and environments to be as usable as possible by as many people as possible, regardless of age, ability or situation.

Public information systems giving information on hazards and risk, warnings of approaching events and advice during and after an emergency on what action to take, often do not present this information in appropriate media or formats for those with sensorial or intellectual impairments. As a result, when disaster strikes, persons with disabilities may not know what to do, where to go, or who to turn to for help. Advice may also be inappropriate, such as telling wheelchair users to take cover under tables in an earthquake.

Methods for communicating risk and early warnings should, therefore, be appropriate to the nature of the impairment. Examples are printed material in large type or Braille for partially-sighted or blind people, sign language or captions on television broadcasts for the deaf or hard of hearing, and face-to-face discussions with people who have learning difficulties or other health problems that may affect their understanding of messages. 'Phone trees' can be used to get messages out to large numbers of targeted individuals, as well as enabling them to alert emergency professionals to their situation.

Those with impaired mobility find it difficult or impossible to take protective action and get out of harm's way quickly. They may be unable to navigate debris inside damaged buildings. In larger buildings, when lifts and escalators stop working, they may be unable to use stairs. Evacuation procedures, designed to move large numbers of people away from a threat as rapidly as possible, may set persons with disabilities aside – in the planning and, even physically during an event – because they are seen as an impediment. When forced from their homes, persons with disabilities may find that emergency facilities (e.g. first-aid stations, emergency shelters, food and water distribution centres) and temporary housing are inaccessible.

Preparedness and response drills therefore need to be practised by persons with disabilities and those who are responsible for assisting them. This saved the lives of a number of people during the attack on the World Trade Center in New York on 11 September 2001. They included the blind and visually-impaired staff of the Associated Blind Organization, based on the ninth floor, which had developed an

evacuation plan and drill for its staff with the help of the New York City Fire Department. Regular practice also helps to identify problems or issues needing further attention. However, persons with disabilities are often excluded from evacuation drills. John Glenn, a business continuity consultant, has observed workplace managers being notified before a drill “so that people with problems can ride the elevators down before the alarm sounds and the elevators stop moving”.

In the chaos and confusion in the aftermath of a conflict or disaster, people with pre-existing impairments may lose family members or carers, be moved to temporary housing or shelter, and lose mobility and other aids, thus increasing their vulnerability. Some will not have been able to flee with their families, and may have been separated or left behind. They may have difficulty accessing information, food, water and sanitation sources. Conflict- or disaster-related injuries put additional strain on health care resources in already severely overstretched countries. Consequently, persons with disabilities are often a low priority in service provision – furthering isolation, social exclusion and marginalization.



Disabled and unable to get to the relief distribution points, this resident of Louisiana relied on daily visits from the American Red Cross in the aftermath of Hurricane Katrina.

Gene Dailey/
American Red Cross

Emergency service workers often fail to understand the specific situation and needs of persons with disabilities. This is particularly evident in the management of emergency shelters. In some instances, persons with disabilities have been turned away from shelters because of volunteers' lack of confidence regarding the shelter's ability to meet their needs. In the January 1994 Northridge earthquake in California, a man with a hearing problem was denied admission to an emergency shelter because its staff could not understand sign language, and people with cerebral palsy were ignored because shelter volunteers thought they were on drugs or alcohol. Other persons with disabilities were turned away from shelters and told to go to hospitals by staff members who assumed that they were sick or injured. After the Kobe earthquake in Japan, people with intellectual disabilities who did manage to get into shelters faced discrimination from the shelters' other occupants and found themselves pushed to the back of food queues. During a cyclone evacuation in Bangladesh, a family brought their child with a disability with them to the cyclone shelter but, because of the negative and hostile attitudes of others in the shelter, they decided to take a chance and return home rather than remain there.

There is evidence that in some of the temporary shelters and camps set up after the Indian Ocean tsunami, some persons with disabilities were not given their medication, for example their anti-epilepsy medication. This resulted in a marked deterioration of their condition.

Disability-awareness training is an essential element in all areas of disaster risk reduction activity. Emergency personnel must know how best to communicate with persons with disabilities, how to assist them and how to use relevant equipment. They should always regard a person with a disability as the expert on his or her disability, and ask them for advice when trying to help them. Few, however, may possess such expertise. For example, shelter staff and volunteers are often trained in first aid or other areas critical to the delivery of emergency services, but many are unfamiliar with the needs of persons with disabilities.

Emergency shelters should be accessible to persons with disabilities, and designed or organized with their needs in mind. For example, this might include the provision of crutches, portable ramps, wheelchairs, medical supplies and equipment, cold storage for essential medication, and facilities for guide dogs, as well as ensuring access to family members and caregivers. Some may ignore advice to leave their homes if they believe that shelters cannot support them.

In all of this, it must be remembered that they are not a homogenous group: as well as capabilities, diversity and differences vary according to a number of other factors, including gender, age, income, caste, tribe, and location. This has a bearing on how disability is mainstreamed into policy and practice.

Agency and activism of persons with disabilities

In theory, disaster risk reduction aims to be inclusive, helping all people at risk but, as has been demonstrated, in practice disaster planners and managers give low priority to persons with disabilities. They are rarely consulted at any level or any stage of the disaster cycle – like most disaster-affected people, from preparedness to recovery – yet they are among those most affected, and least likely to receive assistance.

The notion that all persons with disabilities are unable to help themselves and must be aided or directed by others is widespread, even among agencies that work with

Box 4.4 Skills of blind people can prove lifesaving

Colonel Kenneth A. Silberman is a blind, trained community emergency response team member in the United States. This is his story:

In the fall of 2005, I saw an article in the local newspaper, talking about an upcoming meeting to organize a community emergency response team (CERT). The article said that everyone was welcome and that there were no age or physical requirements. So I went, because I was interested in learning disaster skills that would help me and my neighbours. We were told that the purpose of a CERT team is to give citizens the basic training necessary to provide emergency services in the first 72 hours of a disaster when professional responders and high-tech equipment will be en route but unavailable. I signed up.

The 20-hour course was held at the Maryland Fire and Rescue Institute. It was taught by retired and active emergency medical services (EMS) personnel and covered basic training in disaster preparedness, fire safety, disaster medical operations, light search-and-rescue operations, CERT organization, disaster psychology and terrorism, and concluded with a disaster simulation.

The instructors were nervous about having me on the course but did let me participate. I was able to download the textbook from the FEMA [Federal Emergency Management Agency] web site in accessible Microsoft Word files. I had classmates and home readers help me with other handouts when they were not redundant to the book and not accessible.

The hands-on exercises also went well. Because we were trained to complement each others' skills as teammates, I simply used my white cane or used sighted assistance as appropriate. Conversely, my sighted colleagues relied on me in poor-visibility situations. Blindness skills proved invaluable in the search-and-rescue phase of the training, when we had to traverse a pitch-black, multi-storey maze and apartment looking for victims. There was a lot of panic due to disorientation. However, it was business as usual for me. So, I ended up leading the operation. The instructors and students accepted me completely after that.

As for the equipment, the students had to work with the basics. The first-aid kits consisted of just bandages, compresses and the like.

So there was no instrumentation to read. Real blood would be sticky and warm and would be discernible through gloves. The fire extinguishers were simply point and shoot. I put out the test-stand fire by pointing at the forward base of the heat and sweeping the jet back and forth while moving it toward the back of the fire. In a real fire, the extinguisher will either work or not. The gauge is really for maintenance. Shutting off utilities was easy. Circuit-breakers, gas and water valves were easily felt.

During the advanced Metro Rail [underground] training, my cane skills saved the day again. I had no trouble and used sighted assistance when near the power rail. Blindness skills were critical during a fire simulation in a rail carriage. I was able to cut right through the smoke, grab the emer-

gency kit from under the seat, and direct people to the door at the end of the car. The transit police were very supportive after that.

As a result of all of this training, I was elected as the deputy coordinator of the Greenbelt-CERT in November 2006. I hope that my experience will expand the discussion of disabilities and disaster preparedness to go beyond caring for disabled persons, to making them service providers.

This will prevent responders from diverting their attention from victims to persons with disabilities who are quite capable of taking care of themselves. Secondly, a pool of talented and capable disabled folks are likely to be either not utilized or underutilized. In a real disaster, all hands will be needed on deck. ■

them. At present, many of those organizations that do try to provide special services for them tend to plan from the top down: *for* persons with disabilities, but not *with* them. Yet they are in the best position to assess their needs and plan how to meet them during and after emergencies.

Many persons with disabilities have skills, experience and other capacities that can assist them in a disaster and be utilized by others engaged in disaster risk reduction or emergency response. For example, in a study for the U.S. Geological Survey following the 1989 Loma Prieta earthquake in California, researchers Mansour Rahimi and Glenn Azevedo found that persons with disabilities had a psychological advantage which made them less likely to become injured or to panic during and after the earthquake, “since they negotiate with altered and sometimes difficult physical and environmental limitations on a daily basis” (see Box 4.4).

Local DPOs can be a useful source of information and advice on the location and needs of persons with disabilities. In this way, persons with disabilities and their organizations can also play an active part in preparation, planning, recovery and reconstruction efforts.

Steps can be taken to work with persons with disabilities and to engage them in discussion and training regarding the specific disaster risks the community faces, as

well as how to deal with them, how to improve the security of their homes and workplaces, how to warn them of impending events, how to find a safe place in the event of severe hazards, and how to obtain help if required.

There are numerous examples of how this can be done. The Indian Ocean tsunami did become a catalyst for agencies and planners to rethink their methods, and has put issues such as universal design and accessible reconstruction higher on the agenda. Many examples of peer support emerged in the aftermath of the tsunami. There were many cases of local DPOs in India and Sri Lanka responding to the disaster with few or no resources and little or no funding. When asked why, they simply responded they had to. Disabled Peoples' International (DPI) established a relief fund and regional assemblies assisted persons with disabilities in Aceh, Indonesia.

During and after disaster or conflict situations, many come together out of necessity to form their own DPOs or similar self-help groups. The challenge is to work with these local organizations as equal partners in the reconstruction process, and to build their capacity, particularly during the transitional period. It is vital for organizations to work with DPOs in order to deal with issues relevant to them at a community level, as well as to engage persons with disabilities themselves in the work. DPOs must be included in the wider development/reconstruction agenda (and vice versa). Finally, inclusion of everyone in communities destroyed by disasters or conflict can increase social capital and strengthen social bonds, which can have a positive impact on poverty reduction and sustainable peacebuilding efforts, while further promoting development aims.

Persons with disabilities and their organizations must become involved in the training of staff in disaster management organizations. They can join in as part of community organizations or as volunteers. Increasingly, disaster organizations are encouraging the formation of personal support groups, self-help networks and 'buddy' schemes, whereby groups of people agree to assist an individual with a disability before and during emergencies. The groups typically comprise people known to the person with a disability and trusted by them: they may be family members, friends, neighbours or work colleagues. They are aware of the person's needs, work with them to plan for potential disasters and, where necessary, assist them during crises. Guidelines typically recommend that such groups consist of at least three people in each place where the person with disabilities regularly spends a significant proportion of his or her time each week, to increase the likelihood of someone being available in an emergency.

In Sweden, the Deaf Crisis Group is a group of individuals, both deaf and hearing, who have received training in psychiatric and psychological aspects of disaster management. They cooperate with a number of national partners, including the

Swedish Rescue Services Agency and the National Swedish Board of Health and Welfare.

This more collaborative approach should be taken further. Initiatives to reduce risk must be developed in partnership with persons with disabilities, their support networks and their organizations. For example, discussions with users with disabilities could improve the layout, facilities and organization of emergency shelters.

The Northridge earthquake in Los Angeles in 1994 stimulated a more participatory approach to disaster/disability planning. A group was formed calling itself Disabled People and Disaster Planning. It met between 1996 and 1997 and came up with several recommendations for dealing with problems identified during and after the earthquake. It covered earthquake preparedness, the management of emergency shelters, the training of rescue workers, ways of assisting wheelchair users and communicating information to persons with disabilities, making emergency shelters and services more accessible after a disaster, and sources of online information. In Turkey, after the 1999 earthquakes, a non-governmental organization set up a programme to support deaf people. A core group of deaf people were trained as disaster awareness instructors, with the aim that they should then travel the country training others. By 2002, some 2,000 deaf people had been trained.

Disability rights and legislation

Activism of this kind, which is essential for identifying the needs of persons with disabilities and overcoming problems, can be greatly assisted by appropriate legal backing. This would bring disaster reduction in line with other, rights-based approaches to disability and development. Persons with disabilities are increasingly demanding that they are not simply treated as problems to be solved by planners, but as part of society entitled to equal opportunities and rights (see Box 4.5).

In many countries, legislation prohibiting discrimination on the grounds of disability could be applied to disaster risk reduction and response. For example, in the United States, federal legislation prohibits discrimination in disaster response and recovery on grounds of disability by any federal agency or federally-funded programme, and requires government agencies, including local government, to make their disaster risk reduction and response programmes accessible to persons with disabilities. The city of Chicago requires evacuation plans for persons with disabilities in any commercial or residential building over 80 feet high.

However, financial and administrative capacity, as well as political will, is needed to enforce compliance with such laws and regulations. Ratification of the UN

Box 4.5 Rays of hope in Bam

A new chapter was opened in Iran in removing exclusion and restoring rights for persons with disabilities through the adoption of the concept of inclusive learning. This idea was taken from the World Conference on Special Needs Education in Salamanca in 1994, at which representatives from 92 countries, including Iran, and 25 international organizations emphasized the need to maintain standard regulations on equal opportunities for persons with disabilities. In accordance with the spirit of the Salamanca Declaration, the Iranian government has advocated for the accommodation of all children in schools regardless of their intellectual, physical, social, emotional, linguistic and other conditions.

In Iran, the application of an inclusive learning approach is a process of addressing and responding to the diversity of needs of all students by increasing their participation in learning and in changing social attitudes. At present, all schools are in principle open to all children regardless of their physical and mental condition. However, there still remain schools aimed solely at children with mental disabilities. The existence of the latter is to allow for the process of acceptance and change in social attitudes towards inclusive learning, in particular on the part of parents, given that the ultimate decision on the choice of schools for children with mental disabilities rests with parents.

The necessity to accommodate a diversity of needs and requirements was taken fully into account when the International Federation of Red Cross and Red Crescent Societies decided to get involved in the construction of schools in Bam following the devastating earthquake that struck the city on 26 De-

ember 2003. The earthquake caused significant damage to the city; the destruction of 85 per cent of the buildings in Bam included 131 schools in the city and surrounding villages. This destruction made the rebuilding of the city's educational infrastructure a priority.

The International Federation's initial plan to construct nine standard schools was modified to include the construction of three schools aimed at children with mental disabilities, five standard schools and one model school complex for inclusive learning. The Arg-e-Bam Model School Complex (BMSC) is the product of the inclusive learning process in Iran. The BMSC was established in cooperation with the International Federation, the Iranian Ministry of Education and the UNESCO Tehran Cluster Office (UTCO), and the partners to the project committed themselves to establishing an Inclusive Learning Friendly Environment (ILFE). The Model School Complex includes psychological support and health care, facilities for physical education and sport, technical and vocational education, cultural workshops, an amphitheatre, green spaces, and playgrounds. The school aims to embrace those excluded by the education system and to bring them back into an inclusive educational environment. The school can accommodate 400 students in 17 classrooms at pre-primary, primary and lower secondary levels.

The ILFE approach is based on fundamental elements, including an integrated educational approach to all children irrespective of their background, abilities or learning needs, or those affected directly or indirectly by any disaster or disability. There is a strong emphasis on collaboration, participation and

cooperation among students, teachers, parents and the community. Non-discrimination is an essential component of the ILFE approach. In concrete terms, the inclusive, learning-friendly environment in BMSC entails:

- including all children: girls and boys, those from different backgrounds, abilities, needs and those affected by disaster or disability, and so on.
- being culturally sensitive, celebrating differences, and stimulating learning for ALL children
- involving families, teachers and communities in children's learning
- being gender-fair and non-discriminatory
- promoting opportunities for teachers to learn, and benefit from that learning
- making learning relevant to children's daily lives, and ensuring children take responsibility for their learning
- promoting healthy lifestyles and life skills
- promoting participation, cooperation and collaboration
- keeping safe: protecting ALL children from harm, violence and abuse

The BMSC, which was officially inaugurated on 30 April 2007, has been designed and furnished to meet all the requirements to

become a model school for an Inclusive Learning Friendly Environment. This will be a place where the children have the right to learn to their fullest potential, within a safe and welcoming environment. It places the children at the centre of learning and encourages their active participation in learning.

The Iranian education ministry and UTCO are currently working on training teachers and developing the curriculum for inclusive learning. Dr Abdin Salih, the UNESCO representative in Iran, is confident that the BMSC will bring about a breakthrough in promoting the inclusive learning concept in Iran and neighbouring countries. "The International Federation included the Arg-e-Bam Model School Complex in its construction programme of nine schools in Bam, which should be considered as a major contribution to the reconstruction of the Bam educational system," he said. "BMSC will serve as a model school in Iran and the Asia-Pacific region in creating an inclusive, learning-friendly environment by taking a new approach to teaching. The construction of BMSC has been a good example of successful cooperation between the International Federation and UNESCO." ■

convention at national and international levels should be seen as a priority, as this can be used to uphold national disability legislation.

US disability policy consultant June Kailes argues that persons with disabilities "must be assertive to ensure that our safety needs are included in all emergency planning". They cannot rely on laws, policy-makers, administrations and emergency services to ensure adequate protection and support during disasters. Two important lessons learnt by non-governmental organizations in the United States working with and on behalf of persons with disabilities are: firstly, that they cannot rely on official disaster management agencies to provide all the necessary services; secondly, that disability NGOs and disabled people's organizations need to work together more, with each other as well as with official agencies.

Conclusions and recommendations

There are a number of practical recommendations that will not only do much to overcome the challenges relating to disability in all kinds of disaster contexts, but will also stimulate the kinds of attitudinal and institutional shifts that are ultimately needed to ensure their full inclusion in society and development.

Persons with disabilities need to be actively engaged at all levels (national and international) of disaster and emergency planning, disaster risk reduction, and recovery and reconstruction projects.

DPO capacity in disaster-prone countries needs to be strengthened, and included at all levels of planning, prevention and disaster risk reduction, while protection measures in the immediate aftermath of such crises need to be inclusive of, and accessible to, persons with disabilities.

In addition, support needs to be provided for DPOs in the dissemination of information about the UN convention, and in monitoring and assessing its implementation.

The drafting of IASC guidelines on inclusion would aid the implementation of policies and practices highlighted in this chapter, as well as acting as a lobbying and awareness-raising tool.

At the same time, a commitment should be made to mainstream disability across all humanitarian organizations, in line with Article 32 of the UN convention. Mainstreaming disability requires a multisectoral approach. This means that all areas of humanitarian and emergency intervention – from water and sanitation through to education – should be accessible to all.

Agencies involved in disaster preparedness and response, including UN agencies, NGOs, and the International Federation of Red Cross and Red Crescent Societies, should incorporate training and support using a rights-based approach at field level. This will facilitate better needs assessments at the early stages of planning. DPOs should also be involved in the planning and conducting of such needs assessments.

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blind, trained community emergency response team member in the United States. Box 4.5 was contributed by Mehrnaz Komejani, Researcher of the Disabled Schools Organization and Member of the Board of Professors of Tehran Azad University and by Chang Hun Choe, Representative of the International Federation of Red Cross and Red Crescent Societies in Iran.

Note

This chapter uses the terminology referred to in the UN Convention on the Rights of Persons with Disabilities.

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Web sites

Benfield UCL Hazard Research Centre

www.benfieldhrc.org/disaster_studies/disability&disasters/d&d_index.htm

Disability Resources, Disaster Preparedness for People with Disabilities

www.disabilityresources.org/DISASTER.html

Handicap International www.handicap-international.org/

International Disability and Development Consortium www.iddc.org.uk

Leonard Cheshire International www.lcint.webbler.co.uk

UN Convention on the Rights of Persons with Disabilities

www.un.org/disabilities/convention/facts.shtml

World Bank, Disability www.worldbank.org/disability

World Programme of Action Concerning Disabled Persons

www.un.org/esa/socdev/enable/diswpa01.htm