review paper

ENVIRONMENTAL HAZARDS
Human and Policy Dimensions

Disability and public shelter in emergencies

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This paper reviews current practice regarding people with disabilities in public (or communal) emergency shelter management. It shows that provision for disabled people generally fails to meet their needs and describes the main problem areas. These problems are set in the context of management and staff failings as well as underlying weaknesses in disaster management structures as a whole. The latter include outdated attitudes towards disability, the invisibility of people with disabilities to emergency officials and relief workers and misguided assumptions about the capacities of disabled people and their organizations to manage and respond to crises. The paper concludes with suggestions about how these challenges might be overcome.

Keywords: disability; displaced populations; emergency response; evacuation; vulnerable groups

1. Introduction

There are estimated to be over 600 million people with disabilities[1] worldwide: 80 per cent of them live in developing countries, many of which are disaster-prone. Disabled people are highly vulnerable to disasters, more on account of social marginalization than impairments (Kett and Twigg, 2007). This paper presents findings of a review of current practice regarding people with disabilities in public (communal) emergency shelter management: by public emergency shelter we mean any building or facility used for the purpose of sheltering large numbers of people during and after emergencies, be it purpose-built or taken over at times of crisis. We reviewed documents on disability in emergency preparedness and response to natural hazard events; much of this was 'grey' literature from operational agencies. Only recently has a body of literature on disabled people's vulnerability to disaster, the social impact of disasters on disabled people and appropriate models of disaster management begun to emerge (Hemingway and Priestley, 2006), much of it being from the USA. Nevertheless, there is a growing and consistent body of evidence from different parts of the world showing that: people with disabilities are disproportionately affected by disasters; emergency preparedness, response and recovery operations are planned and implemented with little regard for their needs and capacities; lesson learning is weak even where problems are identified; and progress towards inclusion is very slow (HarrisInteractive/National Organization on Disability, 2004; Cordeiro and Deshpande, 2005a,b; IDRM, 2005; National Council on Disability, 2005; Kett and Twigg, 2007; Clive et al., 2010; Wisner, in press).

The subject of public emergency shelters is neglected even within the literature on disability and disasters (National Council on Disability, 2009, p. 125). Attention is given to other issues, such as warning delivery and response, evacuation from homes and public buildings, aid distribution and recovery assistance. Moreover, the discussion of emergency communal shelters and disability proceeds largely from the standpoint

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of medical and charity models of disability. The medical model defines disabled people individually by their impairments and offers medical or technical solutions. The charity perspective is that disabled people are merely to be pitied and helped. Disability rights' advocates press for adoption of a social model, based on human rights, which sees disability as the social consequence of having an impairment: therefore, the inequalities faced by disabled people can only be overcome if society becomes less discriminatory and more inclusive (Kett et al., 2005; Clive et al., 2010).

2. Good practice (the normative model)

The main elements of good disability practice in communal shelter management can be summed up as follows (National Council on Disability, 2005; National Organization on Disability, 2005b; Oosters, 2005; Gibson and Hayunga, 2006; US Department of Justice, 2007a,b; Federal Emergency Management Agency, 2008; Kailes, 2008; Curtin, 2009; Clive et al., 2010):

- ensuring equal access (this includes accessible parking, exterior routes, entrances, interior routes to the shelter area and toilets serving the shelter area);
- shelter staff (professional and volunteer) are trained in meeting disabled people's needs and plan for these in advance;
- availability of food, including special diets;
- provision of technical support (e.g. access to electricity for medical and mobility devices and refrigeration for medication);
- use of appropriate methods of communication (visual, audio and interpreters);
- appropriate and sufficient medical and volunteer assistance is available (including families, personal support networks and, where appropriate, care animals);
- promoting and sustaining disabled people's independence and safety when sheltering;
- involvement of people with disabilities in shelter planning;
- monitoring and evaluating shelter activity and practice;
- assistance in returning home, or provision of/assistance in finding temporary accommodation for those unable to return to their homes immediately after an event.

3. Experiences from disasters

The literature indicates strongly that public shelter provision for disabled people in emergencies generally fails to meet their needs (Blanck, 1995; Anam et al., 2002; National Council on Disability, 2005; 2006a,b; 2009; Oosters, 2005; Freking, 2006; Gibson and Hayunga, 2006; Hemingway and Priestley, 2006; National Organization on Disability, 2006; White et al., 2007; Kailes, 2008; Clive et al., 2010; Noman Khan and Bari, undated). The following problems are widespread, throughout the world.

Access (physical):

- access routes that disabled people cannot use;
- shelters that are physically inaccessible (location or entrance facilities).

Admission:

- people with disabilities refused admission to shelters on the grounds that the shelters cannot manage their disability and they should seek specialist facilities (particularly those with mental health issues).

Needs assessment:

- registration and assessment procedures that fail to pick up special needs, particularly functional needs (in addition to the lack of pre-existing special needs registries).

Facilities:

- lack of accessible restrooms, cots, toilets, bathrooms, showers.

Food:

- difficulty in getting access to meals that are provided;
- lack of options for specific dietary needs (e.g. people unable to chew, diabetics).

Medication:

- problems accessing medication, medical equipment and medical supplies;
- problems with assistance in refrigerating medication.

Communications:

- telephone and other communications equipment inaccessible;
- lack of or inadequate signage, captioning and translation in communicating messages.

Personal support:

- family members, carers and members of personal support networks with skills in supporting people with functional needs discouraged from accompanying them into shelters or denied access;
- no provision made for service animals, leading to their exclusion from shelters;
- marginalization and discrimination by other shelter users, particularly in crowded shelters.

The harmful effects of such practices were frequently exemplified during Hurricane Katrina in the USA in 2005. Regarding access to medical facilities, for instance, a volunteer in one shelter recorded that:

> I have seen many frail people struggle to climb or descend the stairs in order to get medical attention, and I have personally seen two very exhausted men in wheelchairs almost decide to forego triage or other medical attention because of the difficulty of accessing this unit (National Council on Disability, 2006a).

Elsewhere, inadequate communication marginalized deaf evacuees in accessing support services:

> Because the majority of the deaf evacuees used American Sign Language, few of the shelter volunteers could communicate with them . . . The deaf evacuees missed out on important announcements that streamed through the public address systems of the large shelters. The announcements instructed evacuees which line to stand in to get federal financial assistance, which line to go to for medical appointments, and how to register to locate missing relatives. Deaf evacuees never got this information and thus were passed over for services the first week at the shelter (White, 2006, pp. 50–51).

Disabled people's separation from their families and support networks resulted in:

> some people being . . . transferred unnecessarily to medical shelters or nursing homes. Others were not identified because of the lack of trained eyes as well as the lack of or inadequate screening questions. This caused some individuals' conditions to deteriorate to the point that they did require transfer to a hospital, nursing home, or medical shelter (National Organization on Disability, 2006, p. 9).

US research also suggests that lack of transportation, failure of a 'buddy' (personal support) system and the belief that a shelter will be unable to accommodate their specific needs make people with disabilities reluctant to evacuate in response to warnings (National Council on Disability, 2009, p. 129). Where evacuation is more frequent, in response to seasonal hazards, previous unpleasant experience of evacuation shelters may make disabled people reluctant to venture into them again. In Bangladesh, inaccessibility, lack of safety and poor sanitation facilities in cyclone shelters, combined with cultural constraints, deter disabled people, especially women, from taking refuge (Anam et al., 2002, pp. 29–30).

4. Contextualizing shelter management and its failings

Most of the problems listed above are directly attributable to limitations in staffing and management. The literature already cited also demonstrates:

- an acute shortage of shelter personnel trained in planning for people with disabilities, working with them and dealing with their needs;
- lack of co-ordination and communication between emergency managers and between shelters regarding special needs, referrals and acquisition of additional specialist human and material resources;
- failure to survey shelter sites with accessible features in mind; staff not trained to assess shelters for accessibility;
- lack of engagement with disabled people's organizations (DPOs) and other specialist disability organizations, both in disaster planning and during events, to understand disabled people's needs and provide support.

These management and staffing failings reflect underlying weaknesses in disaster management structures as a whole. Many studies identify poor planning for people with disabilities in disasters, confusion about the roles and responsibilities of care giving and emergency management staff and misplaced assumptions among emergency managers that disability service providers can meet all disabled people's needs in a crisis (Clive et al., 2010). In its review of performance in Hurricane Katrina, the US National Organization on Disability concluded that 'All levels of government experienced systemic failures in their efforts to respond to the needs of the disability and aging populations.' (National Organization on Disability, 2006, p. 16), while the National Council on Disability noted that 'many of the problems . . . are systemic in nature and were not caused solely by the hurricanes. The challenges faced by people with disabilities during and after the hurricanes, while unique in scope and proportion, were similar to the challenges people with disabilities face on a day-to-day basis' (National Council on Disability, 2006a).

The scale of this institutional challenge is indicated by the repeated failure to learn lessons from past experience. According to the US National Council on Disability:

> Many of these barriers are not new. Information and lessons learned are not shared across agency lines, and thus experience does not enlighten the development of new practices. Many accessibility lessons learned during previous disasters are not incorporated in subsequent planning, preparedness, response, and recovery activities . . . Lessons learned after each disaster about physical, communication, and program access for recovery centers, and other structures and buildings used in connection with disaster operations (e.g. first aid stations, mass feeding areas, portable payphone stations, portable toilets, and temporary housing, as well as shelter identification, access, management, training, and services) do not appear to get integrated into subsequent practice (National Council on Disability, 2005, pp. 11, 42).

Deeper attitudinal problems underpin this reluctance to change. One is the persistence of the medical model of disability in emergency management, whereby people with disabilities are seen purely in terms of their specific disabilities. This causes them to be barred from many public shelters on the misguided assumption that they need specialist support and facilities that are not available in the shelters (e.g. National Council on Disability, 2005, p. 19; National Organization on Disability, 2006, p. 13). It also leads to them being separated from their support networks and communities. A more effective approach, now being advocated, is to use a flexible framework addressing a broad set of function-based needs (e.g. communication, medical, maintaining functional independence, supervision and transportation) and reflecting the capabilities of the individual, irrespective of any specific diagnosis or status (Kailes and Enders, 2007; Federal Emergency Management Agency, 2008; Martin,

2009; National Council on Disability, 2009, pp. 316–317). Adoption of this approach could lead to 'a paradigm shift in emergency planning in that it fosters the development of an operational set of predictable supports' (Parsons and Fulma, 2007).

Disabled people remain largely invisible to emergency officials and relief workers. This is revealed, for example, by the view commonly held by emergency staff that there are very few people with disabilities in a disaster-affected area even when it should be obvious that there are many more (Kett et al., 2005, pp. 13, 17). As US disability and disaster specialist June Kailes points out, 'Most disaster response systems are designed for people who can walk, run, see, drive, read, hear, speak and quickly understand and respond to instructions and alerts' (Kailes, 2008, p. 10). Even basic information on numbers and location of disabled people is likely to be missing or inadequate (Kett and Twigg, 2007). A study of community organizations and public safety agencies in California, in 1984, revealed that 'relatively little activity had taken place' in emergency planning for disabled people (Tierney et al., 1988, pp. 84–88). Interviews with local emergency managers in Manila, Mumbai and Mexico City, carried out for a United Nations University study some years ago, indicated that disabled people were not even identified specifically as a vulnerable group (Wisner, in press). After the 9/11 attacks in New York, the Center for Independence of the Disabled reported that 'people at the Red Cross were polite and interested, but everything had to be brought to their attention.' (National Council on Disability, 2005, p. 40). Research after the Indian Ocean Tsunami of 2004 concluded that relief agencies' 'awareness [of disabled people and their needs] was low, with disability not being a topic of discussion at the majority of organizing and co-ordinating meetings' (IDRM, 2005, p. 6); and few relief agencies included disability in their evaluation methodologies (Hemingway and Priestley, 2006, p. 61). In Bangladesh, the variance between official assertions and community views of the level of assistance given to people with disabilities in preparing for disasters and accessing shelters (Anam et al., 2002, p. 32) may be due in part to officials' inability to perceive and understand disability in the community.

If recognized at all, people with disabilities are likely to be put with others into the catch-all category of vulnerable groups, which fails to identify their specific needs. It is not that emergency managers overlook disability alone: there is plenty of evidence to suggest that in many areas of crisis management and disaster response, including sheltering, there are widespread failures to recognize the specific needs of other marginalized and vulnerable groups (e.g. Phillips et al. (eds), 2010). Even when special needs are identified, there may be inconsistency between different emergency organizations in defining such groups and failure to appreciate that disability takes different forms and hence leads to different needs. Oversights and omissions appear almost inevitable in such circumstances (White et al., 2007, pp. 28–29).

With such attitudinal barriers, it is not surprising that disabled people are usually seen as mere passive recipients of aid. DPOs and other organizations representing or supporting them are excluded from planning and implementing emergency response. Researchers in India after the 2004 tsunami found that 'inclusion of disabled people seems to be limited to surveys, receiving relief and aids and equipment, and does not involve inclusion in planning, decision-making or management' (Kett et al., 2005, p. 6). In a US survey after Hurricane Katrina, five out of six emergency managers interviewed reported having a plan in place that included people with disabilities, but only two stated that disability organizations had been involved in the preparation of the plan (White et al., 2007, p. 15). During Katrina, workers in Centers for Independent Living complained that they were denied access to shelters, that emergency staff were uninterested in or unaware of the skills they had to offer or, in some cases, that they were simply 'dumped on' by emergency managers, who referred all disabled people and disability

problems to them (White et al., 2007, pp. 22–23). Even on disability questions, emergency managers are more likely to communicate with other government agencies than with disability organizations, who are kept out of the loop (e.g. White et al., 2007, pp. 18, 22). Much of the communication received by the New Orleans Center for Independent Living in the Katrina disaster was from other disability organizations out-of-state; this resulted in tangible support in the form of money, volunteers, durable medical equipment and clothing. 'The overwhelming response to the question "What type of resources would be most helpful to better serve people they serve in an emergency or disaster?" was the need for better communication and networking at all levels' (White et al., 2007, p. 21).

Agencies that support inclusion, in principle, may not understand its implications in practice (Kett et al., 2005, pp. 26–32). This is not just an accidental feature of disaster response but also a fundamental institutional failing. After the experiences of the 2004 Indian Ocean tsunami, it was claimed that 'Many disabled people have been and are being structurally excluded from relief programmes. Their basic needs are simply not adequately met and their human rights are at best ignored, at worst abused' (Oosters, 2005, p. 8).

5. Ways forward

A wide range of complementary efforts will be required to overcome these problems. These are outlined in the following paragraphs. Here we are principally concerned with solutions to the underlying institutional and other causes of poor shelter facilities and management, rather than with specific technical matters.

There is no shortage of technical guidance on public emergency shelter design although its quality and consistency vary greatly. In Australia and the USA, for example, it is thorough, incorporating a range of disability-related provisions, many of them straightforward (Rossiter and Robinson, 2005; Mullins Consulting, 2006; US Department of Justice, 2007a,b; Nasreddin, 2010). Improved guidance is also becoming available in developing countries (e.g. Handicap International Bangladesh, 2005; Hans et al., 2005; Curtin, 2009). But even recent guidance can be far from sufficient. Official guidelines for the design and construction of cyclone and tsunami shelters published by the Government of India and United Nations Development Programme in 2006, when considering access arrangements and staircases, suggest merely that: 'a ramp with a slope of 1:8 to 1:10 may be considered up to the first floor for carrying physically disabled and elderly people' (Arya and Agarwal, 2006, p. 10), making no mention of other forms of provision for people with disabilities within the shelters.

Examples of successful sheltering demonstrate that good organization and planning are key elements in shelter access and provision for disabled people, at strategic and operational levels. This was certainly the case in evacuations of residents of nursing homes in Florida to avoid Hurricane Charley in 2004 (Kuba et al., 2004), although helped by the fact that these were people already living in institutional environments rather than independently. Duval County, Florida, has implemented an 'Adopt-A-Shelter' programme in partnership with local hospitals and medical supply companies to ensure that special needs shelters are fully stocked prior to disasters, to develop an inventory for these shelters and to provide resources in the event of an emergency (National Council on Disability, 2006a). The Senior Safe Center programme, in place in the states of Alabama and Florida since 2008, involves building and retrofitting dual-purpose centres and shelters for senior citizens (Clive et al., 2010, p. 202). There have been many calls for better registries of disabled people's locations and needs and of the material, financial and human resources that can be called upon to support them in a disaster (e.g. White et al., 2007, pp. 35–36). In the USA new online networking tools are being developed to support this, such as the Special Population Information Registry designed by the Center for Disaster Risk

Policy at Florida State University (www.spinreg.org). There have also been suggestions that geographical information systems technology can be applied to this task (Enders and Brandt, 2007). In Kobe, Japan, a detailed survey and mapping project has been undertaken to identify disabled people living in hazard-prone locations and to raise awareness of their situation and needs in an emergency with disaster planners and among their communities (Tatsuki and Comafay, 2010).

However, addressing underlying institutional weaknesses is essential to achieve widespread and lasting changes in operational practice. The most commonly advocated approach is to sensitize emergency management organizations and their staff through training, guidelines and other technical resources. This is how the Inter-Agency Standing Committee, the main mechanism for co-ordinating international humanitarian assistance, recommends improvement of services to older people, many of whom may have some disability (Inter-Agency Standing Committee, 2008, p. 6). In the USA it has been suggested that such training should be made a pre-requisite for career progression in emergency management (Fox et al., 2007, p. 203).

Such standard prescriptions are necessary but insufficient because they do not address the fundamental principle of inclusion, a point made firmly by the US National Council on Disability after Hurricane Katrina: 'It is important to recognize that some of the challenges faced by people with disabilities who sought assistance in shelters are inherent in any disaster response – the initial general confusion, an inadequate number of trained personnel, etc. However many of the most significant problems could have been avoided with more inclusive emergency planning' (Nation Council on Disability, 2006a). Similarly, the US National Organization on Disability identified several exemplary general population shelters that were accessible to people with disabilities during Katrina. One city mayor designated a convention centre as a general shelter and ensured that it included interpreters for the deaf, accessible shuttle services, internet access, employment opportunities and information on how to find accessible housing. The shelter operators were not experienced emergency managers; rather, the key to their success was their attitude of inclusiveness (National Organization on Disability, 2006).

Legislation regarding equality or requiring providers of public goods and services to ensure that these are accessible to people with disabilities may be an important driver of change in some countries. This is notably the case in the USA where the Americans with Disabilities Act (1990) has stimulated several Federal Government agencies to produce guidance relating to disability and emergency management (e.g. US Department of Justice, undated; US Department of Transportation, 2003). The Act also requires shelters to conduct operations in ways that offer people with disabilities the same benefits (such as safety, comfort, food, medical care, and the support of family and friends) that are provided to people without disabilities (US Department of Justice, 2007a,b; Federal Emergency Management Agency, 2008, p. 25; Kailes, 2008, p. 69). Further legislative and administrative improvements followed hurricanes Katrina and Rita in 2005 (Parsons and Fulma, 2007; Clive et al., 2010, p. 195). County emergency managers surveyed in the USA identified federal government mandates as the single most important reason for modifying county disaster plans, with prompting by people with disabilities being a very minor factor in driving change (Fox et al., 2007, p. 200).

However, it cannot be assumed that legislative change will translate easily and quickly into change on the ground. It was some years before the Americans with Disabilities Act began to make its mark on formal guidelines, while the University of Kansas 'Nobody Left Behind' study (2003–5) found that only 27 per cent of the county emergency managers surveyed had completed the Federal Emergency Management Agency's Emergency Planning and Special Populations course and only 20 per cent had specific guidelines in place to help people with disabilities in disasters (Fox et al., 2007, pp. 201–202). In India the Persons with Disabilities Act 1996 was

said after the 2004 tsunami to have 'failed to produce a noticeable change in society', with 'slow implementation of its provisions'. Planning and designs for post-tsunami housing and reconstruction programmes there seem largely to have ignored access and other disability issues (IDRM, 2005, pp. 17, 23–25, 32–35). A similar situation was encountered in Indonesia, where the provisions of the 1997 Act Concerning People with Disabilities were not echoed in pre-tsunami disaster plans and procedures and little attention was paid to disabled people in post-tsunami disaster planning (IDRM, 2005, pp. 42–54).

More specific legal provisions or standards may be required to bring about measurable changes on the ground in areas such as access arrangements and provision of accessible toilets and bathrooms (e.g. Kailes, 2008, pp. 70–71). The issue of appropriate disability standards for emergency preparedness is currently attracting attention and discussion in the USA, for instance, although the emphasis is on emergency communication and evacuation issues (American National Standards Institute, 2009). Standard setting is potentially valuable in improving shelter management, but there have been warnings about the needs for disabled people's participation in these processes; for clear expectations about what standards can deliver; and about ensuring that they are seen as issues for the whole community, not merely the disabled, to address (American National Standards Institute, 2009). Internationally, the latest revision of the Sphere Project's Humanitarian Charter and Minimum Standards in Disaster Response (Sphere Project, 2010), due to be published in 2011, is taking disability more seriously as a cross-cutting issue although the standards do not contain any specific standards for people with disabilities in communal emergency shelters (Kett, 2010).

Universal standard setting is contentious, since resources and capacity are so unevenly distributed. A complaint made in a US National Organization on Disability report regarding communications with deaf or hard-of-hearing evacuees from Katrina – that less than 30 per cent of shelters had access to American Sign Language interpreters, 80 per cent did not have text telephones, and 60 per cent did not have televisions with open caption capability (National Organization on Disability, 2006, pp. 8–9) – implies that provision of such services should be easily attainable, a notion that would be considered idealistic in many countries. Even the seemingly more down-to-earth approach of posting written announcements for people who are deaf or hard of hearing has limited value where literacy levels are low.

Moreover, the issue of disability standards in emergencies ought not to be separated from the application of disability standards in society at large. Since many public emergency shelters are not purpose-built but other public or private buildings (e.g. schools, community centres, sports halls) taken over in a crisis, their design and daily use should already be governed by appropriate regulations on such matters as inclusive access and signage, for which the legal responsibility rests with their regular owners and operators. Where this is lacking, advocacy for improved standards or compliance cannot focus on emergencies alone but has to target this wider context.

Adoption of rights-based approaches to disability in disasters has been advocated as a key to overcoming many of the problems faced by people with disabilities, in the longer term. It has been argued that 'the human rights of persons with disabilities should receive priority and that each individual has a right to a basic level of public safety. The acceptance of the existence of such a right carries with it the moral duty to ensure that this right is manifested and protected in disaster mitigation policy' (Parr, 1997, p. 2). Furthermore, 'Addressing fundamental issues of rights, inclusion and equality are effective ways of tackling vulnerability in itself. Disabled people may require many of the same support structures, aid and interventions as may other sections of the population ... For example, the basic needs in immediate post-emergency phases are the same for all – water, shelter, food, sanitation,

etc. It is how they are provided that makes the difference' (Kett, 2007, p. 160).

Such advocates have taken heart from the UN Convention on the Rights of Persons with Disabilities (2008), which is based on the social model of disability. Its aim is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' and it calls on signatories to 'adopt all appropriate legislative, administrative and other measures' for the implementation of these rights. Its wide-ranging provisions include (Article 11) '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' (United Nations General Assembly, 2006, pp. 7–8, 12). The Convention has sparked off some serious discussions about inclusion and mainstreaming of disability into sustainable development (e.g. Yousif and Shaw (eds), 2008), but there is little indication yet of serious penetration into humanitarian assistance thinking and planning. While it will support the promotion of the protection and full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, it should not be seen as a panacea for the eradication of discrimination and inequality. Much relies on how the Convention will be implemented, monitored and evaluated at the national level (Kett et al., 2009).

Disabled people and their organizations have insisted, repeatedly, on their right to be active stakeholders in emergency planning and action, a point made emphatically in the 2007 'Verona Charter':

> Persons with disabilities and their organisations need to be actively involved in decision-making processes concerning situations of humanitarian emergencies and the occurrence of natural and man made disasters and in all the related emergency management activities. This involvement should be fostered by the development of inclusive policies at all levels starting from organisations of persons with disabilities and families, communities up to national and international organisations/bodies (Verona Charter, 2007).

In the USA guidance has been available to disabled people for some time on how to prepare for emergencies, including creating personal support networks, communicating and liaising with disaster management staff and becoming involved in emergency planning processes (American Red Cross, 1997; Kailes, 2002). Such guidance is now also recommending that people with disabilities consider how their needs might be met in public shelters (National Organization on Disability, 2005a). Nevertheless, there is evidence that disabled people and disability organizations or support groups are often not sufficiently prepared for emergencies (White et al., 2007, pp. 14–15, 29–31). There needs to be more investigation and testing of appropriate processes for liaison and negotiation between people with disabilities and shelter staff.

The need for disabled people and their organizations to be more involved in emergency planning as a whole, which is a key component of disability organizations' advocacy on disasters (Kett et al., 2005; National Organization on Disability, 2005b, 2006; Parsons and Fulma, 2007; Kailes, 2008; Wisner, in press), is also beginning to be acknowledged by policy makers (National Council on Disability, 2005; US Department of Homeland Security, 2005, p. 38). This requires the creation of networks and partnerships at all levels well in advance of emergency events, as recognized in recent guidance by the Federal Emergency Management Agency in the USA: 'emergency managers should draw from the skills and resources within special needs planning networks' (Federal Emergency Management Agency, 2008, p. 25); and it should lead to the deployment of community and other organizations in support of official agencies during events.

Many DPOs and disability organizations are involved in emergency response and relief provision to meet needs and fill gaps, but not

necessarily in a planned and co-ordinated way or within the mainstream disaster assistance system. Global disability networks were quick to react with funding and material support after the 2004 tsunami and there was a similar prompt and well-networked reaction by US disability organizations after Katrina (Hemingway and Priestley, 2006, p. 63). In Katrina, US non-profit disability organizations stepped in to provide disabled people in shelters with support resources that the shelters lacked (e.g. teletypewriters, wheelchairs, walkers, oxygen) (National Council on Disability, 2006a), while a deaf people's church which provided food, clothing, children's toys, household items, hearing aids and other equipment to deaf evacuees in the Houston Astrodome 'essentially became a social agency and a center for social support for the evacuees' (White, 2006, p. 51). A decade earlier, a group in Los Angeles called Disabled People and Disaster Planning (DP2) had produced guidance arising from the experiences of the 1994 Northridge earthquake; this included advice to shelter managers on working with people with disabilities and making shelters more accessible (Wisner, in press).

Nevertheless, there is still little linking between civil society organizations representing or working for disabled people and emergency management systems. This has led to the call for efforts 'to raise the awareness of persons with disabilities to the hazards of not being proactively involved in disaster planning at both the personal and community levels. Emergency managers must be willing to reach out to the disability community more aggressively, but it is incumbent on members of the disability community to also reach out to emergency managers if they ignore this opportunity' (Fox et al., 2007, p. 203). In a US study after Hurricane Katrina, 85.7 per cent of 'disability and aging specific organizations … answered that they did not know how to link with the emergency management system' (National Organization on Disability, 2006, p. 7), echoing the findings of an earlier study which found that 53 per cent of people with disabilities surveyed did not know whom to contact regarding emergency plans for their community (National Organization on Disability, 2005b, p. 7). General guidance on building such links is starting to become available (e.g. National Organization on Disability, 2005b) and in the USA a few instances of such partnerships have been identified (e.g. National Council on Disability, 2005, pp. 46–54; 2009, pp. 299–300). Since Katrina, special needs planning groups (comprising disability and ageing organizations, other voluntary organizations working in disasters, health care providers, emergency management and first-response agencies and other institutions such as housing agencies) have begun to form at federal, state and local levels (Clive et al., 2010, pp. 206–207). In displaced persons' camps in Sudan, HelpAge International has set up older people's committees to carry out needs assessments, liaise with other agencies, share information and monitor and assist in distribution of food and other essentials (Wells, 2005, p. 10). An initiative being tested in California is the formation of Functional Assessment and Service Teams, comprising government and NGO volunteers with knowledge and understanding of disability communities, often themselves people with disabilities, who can go into shelters to assess unidentified or unmet needs, solve problems rapidly through provision of materials and services, negotiate with emergency staff and assist the transition back into communal living (Kailes, 2008, pp. 77–84). In India, establishment of targeted disaster advocacy, outreach and information services has been recommended as a key element of disaster response strategy, to distribute information to vulnerable people, identify the needs of the older and disabled population, collate evidence and assist disabled people to obtain access to relief and recovery services (SEEDS, 2001, pp. 50–53). Further research into the effectiveness of these partnerships, the processes involved in creating and maintaining them and the factors that stimulate or inhibit partnerships, in different contexts, would improve our understanding of how to make progress. One factor that is likely to be significant was identified in a US study, which, in

recommending measures to improve services and facilities had to acknowledge that 'many of them will require the investment of the scarcest resource available: time on the part of already over-burdened staff of CILs [Centers for Independent Living] and local emergency management agencies' (White et al., 2007, p. 27).

Representation and leadership are critical issues. One of the messages from a recent workshop on emergency planning for disabled people organized by the American National Standards Institute was the need for 'ensuring adequate representation in leadership roles' (American National Standards Institute, 2009, pp. 2–3). A report for the National Institute on Disability and Rehabilitation Research after Hurricane Katrina went further, arguing that the existing network of Centers for Independent Living, should be given a 'leadership role in a process of bringing together disability organizations including CILs, as well as state and local emergency planners, to develop mechanisms to increase information sharing, coordination, and the development of disaster preparation and emergency response plans that incorporate people with disabilities', by such means as forming planning committees, working with emergency agencies to improve their plans, providing staff to act as contact points during emergencies and stimulating local disability organizations to engage (White et al., 2007, p. 28). One recommendation after Katrina was that parallel teams specializing in issues of disability and ageing should be put in place to work alongside the decision-making structure set out in the US National Response Plan (National Organization on Disability, 2006, p. 10).

This implies action by all relevant stakeholders, or in the words of the voluntary Verona Charter on the rescue of persons with disabilities: 'The safety of persons with disabilities in situations of humanitarian emergencies and the occurrence of natural and man made disasters is the responsibility of organizations of persons with disabilities, single individuals, public institutions at all levels, business and civil society, social partners, non-governmental organizations, educational institutions, health authorities and civil protection organizations.' (Verona Charter, 2007). To judge from the documented experiences of people with disabilities in emergency evacuation shelters, this goal is still a long way off.

Note

1. In this paper we use the terms 'disabled people' and 'people with disabilities' interchangeably although there is some debate among the disability community about which is more appropriate; the latter term is more commonly accepted in North America.

References

American National Standards Institute, 2009. *Final Workshop Report: Emergency Planning for Persons with Disabilities and Special Needs*. American Standards Institute, Washington, DC, USA.

American Red Cross, 1997. *Disaster Preparedness for People with Disabilities*. American Red Cross, Washington, DC, USA.

Anam, N., Noman Khan, A. D. M., Bari, N. and Alam, K. J., 2002. *Unveiling Darkness: The Situation Analysis on Disaster and Disability Issues in the Coastal Belt of Bangladesh*. Centre for Services and Information on Disability, Dhaka, unpublished paper.

Arya, A. S. and Agarwal, A., 2006. *Guidelines for Design and Construction of Cyclone/Tsunami Shelter*. Ministry of Home Affairs. Government of India – UNDP Disaster Risk Management Programme, New Delhi.

Blanck, P. D., 1995. *Disaster Mitigation for Persons with Disabilities: Fostering a New Dialogue*. Washington Annenberg Program, Washington, DC, USA.

Clive, A., Davis, E. A., Hansen, R. and Mincin, J., 2010. Disability. *Social Vulnerability to Disasters*, B. D. Phillips, S. K. Thomas, A. Fothergill and I. Blinn-Pyke (eds). CRC Press, Boca Raton. 187–216

Cordeiro, V. J. and Deshpande, S. S., 2005a. *Research Report on Disability and the Tsunami in India. Part I.* International Disability and Development Consortium, Brussels.

Cordeiro, V. J. and Deshpande, S. S., 2005b. *Research Report on Disability and the Tsunami in India. Part II.* International Disability and Development Consortium, Brussels.

Curtin, M., 2009. *Guidelines for Creating Barrier-free Emergency Shelters*. Handicap International Nepal, Kathmandu.

Enders, A. and Brandt, Z., 2007. Using geographical information system technology to improve emergency management and disaster response for people with disabilities. *Journal of Disability Policy Studies*, 17. 223–229.

Federal Emergency Management Agency, 2008. *Interim Emergency Management Planning Guide for Special Needs Populations*. Federal Emergency Management Agency, Washington, DC, USA.

Fox, M. H., White, G. W., Rooney, C. and Rowland, J. L., 2007. Disaster preparedness and response for persons with mobility impairments: results from the University of Kansas nobody left behind study. *Journal of Disability Policy Studies*, 17. 196–205.

Freking, K., 2006. *Mentally Disabled Faced Bias Post-Katrina*. Associated Press, Washington, DC, USA. www.ncd.gov/newsroom/inthenews/disabled_faced_07-14-06.htm (accessed online 30 November 2006).

Gibson, M. J. and Hayunga, M., 2006. *We Can do Better: Lessons Learned for Protecting Older Persons in Disasters*. AARP Public Policy Institute, Washington, DC, USA.

Handicap International Bangladesh, 2005. *How to Include Disability Issues in Disaster Management, following Floods 2004 in Bangladesh*. Handicap International Bangladesh, Dhaka.

Hans, A., Sharma, R. K., Mohanty, R. and Mishra, P., 2005. *Training Manual for Inclusion of Disability in Disaster Response*. Shanta Memorial Rehabilitation Centre, Bhubaneswar.

HarrisInteractive/National Organization on Disability, 2004. *Emergency Preparedness Survey: Final Report*. HarrisInteractive/National Organization on Disability, Washington, DC, USA.

Hemingway, L. and Priestley, M., 2006. Natural hazards, human vulnerability and disabling societies: a disaster for disabled people?. *Review of Disability Studies*, 2(3). 57–67.

Inter-Agency Standing Committee, 2008. *Humanitarian Action and Older Persons: An Essential Brief for Humanitarian Actors*. Inter-Agency Standing Committee, Geneva.

IDRM, 2005. *Disability and Early Tsunami Relief Efforts in India, Indonesia and Thailand*. International Disability Rights Monitor/Center for International Rehabilitation, Washington, DC, USA.

Kailes, J. I., 2002. *Emergency Evacuation Preparedness: taking Responsibility for your Safety. A Guide for People with Disabilities and other Activity Limitations*. Center for Disability and the Health Professions, Western University of Health Sciences, Pomona, CA.

Kailes, J. I., 2008. *Southern California Wildfires After Action Report*. Center for Disability and the Health Professions, Western University of Health Sciences, Pomona, CA.

Kailes, J. I. and Enders, A., 2007. Moving beyond 'special needs': a function-based framework for emergency management and planning. *Journal of Disability Policy Studies*, 17. 230–237.

Kett, M., 2007. Conflict recovery. *Disability and Inclusive Development*, T. Barron and P. Amerena (eds). Leonard Cheshire International, London. 155–186.

Kett, M., 2010. Personal communication from Dr Maria Kett, Focal Point for Disability in the Sphere Project Handbook Revision 2011.

Kett, M. and Twigg, J., 2007. Disability and Disasters: Towards an Inclusive Approach. *World Disasters Report 2007: Focus on Discrimination*. International Federation of Red Cross and Red Crescent Societies, Geneva. 87–109.

Kett, M., Stubbs, S. and Yeo, R., 2005. *Disability in Conflict and Emergency Situations: Focus on Tsunami-affected Areas*. International Disability and Development Consortium, Brussels.

Kett, M., Lang, R. and Trani, J.-F., 2009. Disability, development and the dawning of a new convention: a cause for optimism?. *Journal of International Development*, 21(5). 649–661.

Kuba, M., Dorian, A., Kuljian, S. and Shoaf, K., 2004. *Elderly Populations in Disasters: Recounting Evacuation Processes from Two Skilled-Care Facilities in Central Florida, August 2004*. Natural Hazards Center, Boulder, Quick Response Report 172.

Martin, K., 2009. *A Shared Responsibility: The Need for an Inclusive Approach to Emergency Planning for People with Disabilities*. Coalition of People with Disabilities, Vancouver, BC.

Mullins Consulting, 2006. *Design Guidelines for Queensland Public Cyclone Shelters*. Queensland Government Department of Public Works, Brisbane.

Nasreddin, H., 2010. *Literature Review on Structural Design of Shelters for People with Disabilities*. University College London, Department of Civil, Environmental and Geomatic Engineering, unpublished report.

National Council on Disability, 2005. *Saving Lives: Including People with Disabilities in Emergency Planning*. National Council on Disability, Washington, DC, USA.

National Council on Disability, 2006a. *The Impact of Hurricanes Katrina and Rita on Persons with Disabilities: A Look Back and Remaining Challenges*. National Council on Disability, Washington, DC, USA. www.ncd.gov/newsroom/publications/2006/hurricanes_impact.htm (accessed 10 May 2010).

National Council on Disability, 2006b. *The Needs of People with Psychiatric Disabilities during and*

after Hurricanes Katrina and Rita: Position Paper and Recommendations. National Council on Disability, Washington, DC, USA. www.ncd.gov/newsroom/publications/2006/peopleneeds.htm (accessed 28 May 2010).

National Council on Disability, 2009. *Effective Emergency Management: Making Improvements for Communities and People with Disabilities*. National Council on Disability, Washington, DC, USA.

National Organization on Disability, 2005a. *Prepare Yourself: Disaster Readiness Tips for People with Disabilities*. National Organization on Disability, Washington, DC, USA.

National Organization on Disability, 2005b. *Guide on the Special Needs of People with Disabilities for Emergency Managers, Planners and Responders*. National Organization on Disability, Washington, DC, USA.

National Organization on Disability, 2006. *Report on Special Needs Assessment for Katrina Evacuees (SNAKE) Project*. National Organization on Disability, Washington, DC, USA.

Noman Khan, A. H. M. and Bari, N., undated, *Disabled People in Flood Situation: Suggested Interventions for Post Flood Rehabilitation of Disabled People*. National Forum of Organizations Working with the Disabled, Dhaka.

Oosters, B., 2005. *Looking with a Disability Lens at the Disaster Caused by the Tsunami in South-East Asia*. CBM International, Brussels.

Parr, A., 1997. Disasters and human rights of persons with disabilities: a case for an ethical disaster mitigation policy. *Australian Journal of Emergency Management*, 12(4). 2–5.

Parsons, B. S. and Fulma, D., 2007. *The Paradigm Shift in Planning for Special-Needs Populations*. Paper to 2007 FEMA Emergency Management Higher Education Conference, Washington, DC, USA, Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities. www.disabilitypreparedness.gov/paradigm.htm (accessed 21 May 2010).

Phillips, B. D., Thomas, S. K., Fothergill, A. and Blinn-Pike, L. (eds), 2010. *Social Vulnerability to Disasters*. CRC Press, Boca Raton.

Rossiter, J. L. and Robinson, D. M., 2005. *Design guidelines for Australian Public Cyclone Shelters*. Paper to International Symposium on Disaster Reduction on Coasts, Monash University, Melbourne, 14–16 November.

SEEDS, 2001. *High Powered Committee on Disaster Management Report on Women, Children, Aged and Challenged in Disaster*. Government of India, New Delhi.

Sphere Project, 2010. www.sphereproject.org/component/option,com_frontpage/Itemid,200/lang,english/ (accessed 30 June 2010).

Tatsuki, S. and Comafay, N., 2010. *Evacuation and sheltering assistance planning for special needs population: Kobe Disadvantaged Population Mapping Project*, Paper to International Sociological Association World Congress of Sociology, Gothenburg, Sweden, July 15, 2010.

Tierney, K. J., Petak, W. J. and Hahn, H., 1988. *Disabled Persons and Earthquake Hazards*. University of Colorado Institute of Behavioral Science, Boulder.

United Nations General Assembly, 2006. *Final Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities: Note by the Secretary-General*. New York, United Nations General Assembly A/6/611. http://daccess-dds-ny.un.org/doc/UNDOC/LTD/N06/645/30/PDF/N0664530.pdf?OpenElement (accessed 30 June 2010).

US Department of Homeland Security, 2005. *Individuals with Disabilities in Emergency Preparedness: Executive Order 13347. Annual Report July 2005*. Department of Homeland Security, Washington, DC, USA.

US Department of Justice, undated. *An ADA Guide for Local Governments: Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities*. Department of Justice, Washington, DC, USA.

US Department of Justice, 2007a. The ADA and emergency shelters: access for all in emergencies and disasters. www.ada.gov/pcatoolkit/chap7shelterprog.pdf (accessed 1 December 2009).

US Department of Justice, 2007b. ADA checklist for emergency shelters. www.ada.gov/pcatoolkit/chap7shelterchk.htm (accessed 1 December 2009).

US Department of Transportation, 2003. *Emergency Preparedness Guidelines for People with Disabilities*. Department of Transportation, Washington, DC, USA.

Verona Charter, 2007. *"Verona Charter" on the rescue of persons with disabilities in case of disasters: declaration of the participants in the Consensus Conference held in Verona on 8–9 November 2007*. www.internazionali.ulss20.verona.it/docs/projects/rdd/veronacharter.pdf (accessed 23 March 2010).

Wells, J., 2005. *Protecting and Assisting Older People in Emergencies*. Network Paper 53, Humanitarian Practice Network, London.

White, B., 2006. Disaster relief for deaf persons: lessons from hurricanes Katrina and Rita. *Review of Disability Studies*, 2(3). 49–56.

White, G. W., Fox, M. H., Rooney, C. and Cahill, A., 2007. *Assessing the Impact of Hurricane Katrina on Persons with Disabilities*, University of Kansas, Center on Independent Living/National Institute on Disability and Rehabilitation Research.

Wisner, B. in press. Disability and disaster: victimhood and agency in earthquake risk reduction. *Earthquakes*, C. Rodrigue and E. Rovai (eds). Routledge, London. Draft at www.radixonline.org/disability.html (accessed 30 November 2009).

Yousif, H. M. and Shaw, D. (eds)., 2008. *UN Convention on the Rights of Persons with Disabilities: A Call for Action on Poverty, Discrimination and Lack of Access*. Economic Commission for Africa/Leonard Cheshire Disability, Addis Ababa/London.