



Understanding the impacts of
CLIMATE CHANGE and
ADVERSE WEATHER EVENTS
ON PEOPLE WITH A
DISABILITY AND THEIR CARERS:

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Available on enliven website www.enliven.org.au

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Introduction

This report is an exploration of the impacts of climate change and extreme weather events on people with disabilities and their carers. Most of the information about climate change and disability is found in reports prepared by United Nations agencies, The World Bank, and disability non-government organisations. It tends to be quite general and to focus on aspects of disadvantage experienced by people with disabilities and their carers. The one issue on which there is a small body of research is the experience people with disabilities have of emergencies and extreme weather events.

Throughout this report an explicit link is made between disability and aspects of climate change that are evident in the present time and place. Because climate change is developing slowly, in human terms, many of the impacts are experienced outside Australia or are not yet clear within this country. For example, food insecurity is a predicted impact of climate change but in Australia food insecurity is much more easily linked to structured social disadvantage than the effects of climate, at this time. For this reason discussion in the report focuses on three major impacts of climate change that are clearly visible now: heatwaves, emergencies due to extreme weather events, and resource inequalities that impact on the adaptive capacities of people with disabilities and their carers. The reason these three impacts are emphasised is that climate change adaptation, within the

service sector, has to be built on a foundation of demonstrable client need at this time and in this place.

The population of people with disabilities and their carers is diverse. This report is most relevant to the needs of people with physical and intellectual/developmental disabilities.

The primary audiences for this report are organisations participating in the community based health and human services sectors. A rationale for the participation of these sectors in climate change adaptation is discussed in Appendix 2.



Actions recommended in the literature

For a summary containing more detail of the recommended actions see the cited entry in the literature review data tables on the enliven website.

1. Because climate change amplifies existing risks to health, policies and programs should take a health inequalities approach (Costello 2009:1712). Disadvantaged groups include: those living in poverty or on low incomes; homeless or living in rental or substandard housing; older people and/or those living with disability or chronic illness; socially isolated or living alone; people with limited transport mobility; children; Indigenous people; refugees and newly arrived migrants; and, unemployed people (Johnson 2012: 5, Kailes & Enders 2007).
2. People with disabilities are particularly vulnerable in disaster situations including extreme weather events (Global Partnership for Disability & Development and The World Bank - 2009). People with disabilities are more likely than others to be left behind or abandoned during evacuation, have support networks disrupted, experience discrimination and gaps in access to services and resources during recovery and reconstruction. People with disabilities need personal emergency plans. In addition, mainstream emergency plans need to ensure access to information, resources and facilities for people with disabilities; mainstream emergency planning and disability organisations need to partner in planning and implementation; needs and capacities of people with disabilities need to be mapped, twin track planning needs to be implemented so that mainstream services meet basic needs; and, specialist services contribute their capacity to meet specialised needs. The Bonn Declaration (2007) recommendations summarise an inclusive approach to people with disabilities in emergency situations.
3. Information for people with disabilities about climate change and health needs to be directly accessible (eg in alternate formats as well as in print) and available through health care providers, the internet, friends and family (Williams-Pichota et al 2010).
4. When planning physical facilities or social programs, principles of universal design should be implemented. This is sometimes referred to as inclusive design. Universal design means: the design of products, environments, programs and services are usable by all people, including those with disabilities, to the greatest extent possible, without the need for adaptation or specialised design (United Nations 2006, Fjord & Manderson 2009, National Organization on Disability 2009).

For people with disabilities inclusive environments need to include: accessible built environments and transport; signage and communications for people with sensory impairments; policies and practices that make services such as health, education and employment accessible; addressing knowledge and attitudes that exclude or diminish the self esteem of people with disabilities (WHO 2011 & National Council on Disability 2006). From a disability perspective inclusive design is best approached by asking a set of questions:

- What is it like to be a person with a disability during and after an emergency?
- Can one hear or understand the warnings?
- Can one quickly exit a home or workplace?
- Can one move about the community after evacuating?
- Are there necessary or even vital daily items (medicines, power supplies, medical devices) that are not likely to be available in emergency shelters?
- Are basic services, like rest rooms and showers, available and accessible to people with disabilities?
- Does the person require assistance from a caregiver? (National Council on Disability 2006)

5. The preparatory actions taken by people with disabilities that helped them to survive a disaster were: preparation of a kit containing supplies such as medication, equipment and disability related supplies, food and water; disaster preparedness training, preparation of a personal evacuation plan and registration with emergency assistance registers; self-assessment of risks, capacities and emergency supplies and equipment; building support networks of family, friends and co-workers (See Rooney & White 2007, Uscher-Pines et al 2009; Bethel et al 2011).
6. When planning for emergency evacuations, that try to meet the needs of people with disabilities, it is important to differentiate between four different evacuation scenarios, as each has different implications for planning and decision making, and each calls on different abilities of people. *Protective evacuations* – long term pre-impact responses to emergency situations eg individual precautionary evacuation prior to an event. *Preventive evacuations* – short term pre-impact responses eg a bomb threat requiring movement to another part of a building. *Rescue evacuation* – short term, immediately post impact evacuation eg evacuating a burning building. *Reconstructive evacuations* – long term post impact eg moving evacuees to camps or temporary housing. The three overlying considerations are the behavior of individuals, planned systems, and the built environment. Applying this framework to emergency plans helps to reveal assumptions that may be dangerous to people with disabilities (Christensen, Blair and Holt 2007).

7. Disability organisations need to be included in the planning and implementation of recovery programs to remedy post disaster loss of independence by people with disability, loss of informal support networks, and discrimination in families and communities in the distribution of scarce resources (Priestley & Hemingway 2006). Post disaster case management for people with disabilities needs to be qualitatively different from that for non-disabled people. It is more intense and with more contacts, is of longer duration, and more complex. The complexity of the cases requires case managers to have expertise in the disability service area (Stough et al 2010).



8. When having new buildings designed, or old ones renovated, it is important to consider the capacity of people with disabilities to move around those buildings and, in emergencies, to evacuate. From a systematic literature review (Christensen et al 2006) identified 10 design issues that make a difference for people with disabilities.

9. A study of municipal level disaster planning in the US, and the capacity to meet the needs of people with disabilities, recommended: improved training for emergency managers; raising the awareness of people with disabilities of the need for personal and community level planning, and inclusion of people with disabilities as trainers; integration of emergency planning systems with health care providers and community based organisations; improved surveillance systems to identify people with disabilities and prepare registries and lists of people known to disability organisations; develop warning systems using multiple communication technologies; and, work with disability organisations to promote personal disaster planning (Fox et al 2007).

Recommendation

It is recommended that enliven facilitate interagency partnerships that enhance the adaptive capacity of people with disabilities and their carers in the context of an environment that is changing under the influence of a changing climate. The partnerships should include emergency planners as well as sectors such as housing and employment that impact the equitable participation of people with disabilities and their carers.

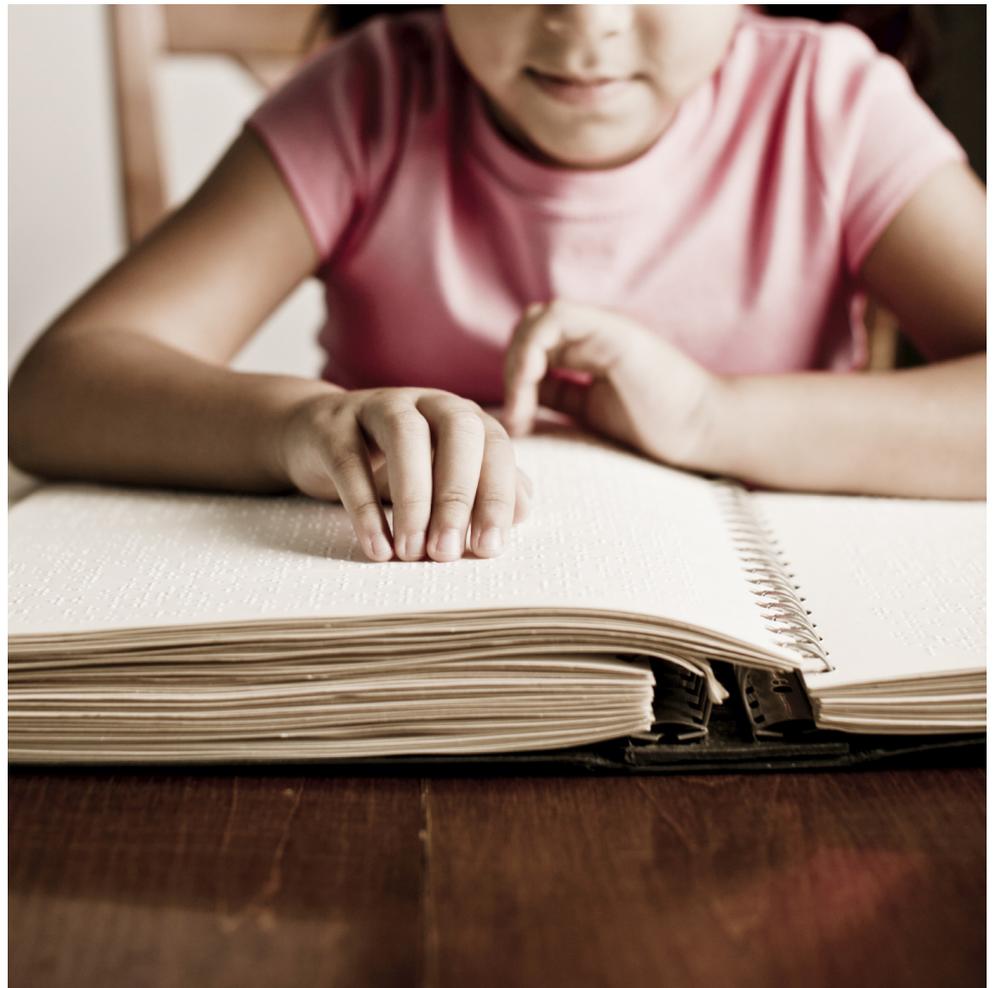


Methods

This report was conceived as a systematic review of published literature on climate change and disability. Normally such a review would focus on published peer reviewed research papers supported by the grey literature comprised of reports and papers from credible organisations. In this case the systematic key word searches of electronic journal databases produced only a small handful of relevant published papers. The poor state of research on climate change and disability is frequently referred to in the existing peer reviewed papers and in the grey literature (for example, The Global Partnership for Disability and Development & The World Bank 2009:5). The one exception to this general observation is the small amount of research literature on relationship between disability and emergencies or disasters. For these reasons most of the material reviewed was identified by: searching specialist journals individually; searching web sites of major non government organisations and some government agencies; and, searching the bibliographies of reports and published papers.

A more extensive account of the search process is to be found in Literature search - Appendix 1.

The documents reviewed have been summarised in either Data table - climate change Appendix 3 or Data table - emergencies Appendix 4.



Climate change

In the table below the major current categories of health risk from climate change, for people with disabilities and their carers, are summarised. The evidence suggests that: extreme weather events; social, economic and demographic dislocation; and heatwaves, are particularly significant for people with disabilities and their carers. There is a frequently expressed argument that, in general, *‘the poorest and weakest groups, such as elderly people, persons with disabilities, children and minorities would be most exposed to climate change consequences’* (Costello et al 2009:1721; Garnaut 2008). The logic of the argument is that *‘because climate change acts mostly as an amplifier of existing risks to health, poor and disadvantaged people will experience greater increments in the disease burden than rich, less vulnerable populations’* (Costello et al 2009:1712).

People with disabilities and their carers share many risks with other disadvantaged populations. However, there is evidence that risks to people with disabilities and their carers in the three climate impact categories in Table 1 are quite specific.

Table 1. Immediate risks to health of people with disabilities from climate change (adapted from Horton et al 2008:10).

Main categories of risks to health (Horton et al 2008:10)	Elaboration on the risks *
1. <i>Health impacts of extreme weather events (floods, storms, cyclones, bushfires etc)</i>	Extreme events cause injury to people, damage to infrastructure (e.g. power, buildings – homes, community facilities and businesses, and water services) and economic activity, leading to contamination and disease, social and economic dislocation and the mental health effects of trauma. People with disabilities and their carers are a population disproportionately affected by extreme weather events.
2. <i>Mental health consequences of social, economic and demographic dislocations.</i> <i>[Note: Limiting health impacts of dislocation to mental health is inappropriate. Dislocation exacerbates the effects of the social determinants of health.]</i>	Disadvantaged populations, including people with disabilities, are expected to have limited capacity to adapt. The health effects are more diverse than simply mental health impacts. For example, when support networks are disrupted and employment, housing and transport, in particular, become less enabling, the impact on capacity for independent living can be substantial.
3. <i>Health impacts of temperature extremes, including heat waves</i>	Heat waves are becoming more common leading to increased morbidity and mortality. Effects vary with duration, timing in the season and vulnerability of the population. People who are very old, very young, people who are frail or have limited capacity to modify their environment are most at risk. This includes people with disabilities.

* Sources used are: Department of Human Services (2007); Russell et al (2009); Garnaut (2008).

Disability

Definitions of disability

There are a number of definitions of disability in current use. The Australian Bureau of Statistics collects data for decision making by government and other institutions. Its definitions of disability focus on functional limitations in daily life. For the national Survey of Disability, Aging and Carers Australia (SDAC) disability is defined as *'any limitation, restriction or impairment which restricts everyday activities and has lasted or is likely to last for at least six months'* (ABS 2010). Using this definition 18.5% of the population has a disability.

In the national census where the intent is to measure the number of people requiring assistance with core daily activities the concern is with the population with profound and severe disability. In this case disability is defined as *'those people needing help or assistance in one or more of the three core activity areas of self-care, mobility and communication, because of a long term health condition (lasting 6 months or more), a disability (lasting 6 months or more), or old age'* (ABS 2011). Using this definition 5.8% of the population has a disability. Although both definitions used by the ABS focus on function they in fact measure different populations making it important identify the definition used when citing any ABS statistics.

International organisations are more likely to focus on the human rights of people with disabilities and adopt a definition that reflects this. The preamble to the United Nations Convention on the Rights of Persons with Disabilities *'recognises that disability*

is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others' (United Nations General Assembly 2007). The World Health Organization (2011:4) develops the United Nations statement in the definition used in the World Report on Disability. *'Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)'*. In the following discussion both the functional and social justice approaches will be discussed in relation to different aspects of climate change adaptation.

Population of people with disabilities and their carers

In the national Survey of Disability, Aging and Carers Australia (2009) 18.5% of the population have a disability. The disability creates specific limitations or restrictions for 16.0% of the population and no specific limitations or restrictions for 2.5% of the population. A small proportion of the population, 1.6%, have limitations on schooling or work only, while 14.4% have limitations on core activities of self care, mobility and communication. The 14.4% is comprised of 5.8% with severe to profound disability and 8.6% with moderate to mild disability (ABS 2010). People with profound or severe disability have the greatest need for assistance.

The proportion of the population with a disability increases with age. Of people 4 years and under 3.4% have a disability, of those who are 65-69 years 40% have a disability, and of those over 90 years 88% do. The causes of physical disability impacting core activities are diverse and include musculoskeletal conditions and disease of the respiratory or circulatory systems, for instance (ABS 2010). For many of these people heat waves and other extreme weather events have significant impacts on wellbeing and capacity to cope with their environment.

Carers of people with disabilities, or people aged 60 years or over, comprise 12% of the Australian population with slightly more females than males in the carer role (ABS 2010).

The commonest forms of disability vary with age. For children under 15 years intellectual disability is most common (4%), for people 15-64 years the most common is a physical disability (11%), and for those aged 65 years and over the most common is a physical disability (40%), followed by sensory limitations and speech impairment (25%) (VicHealth 2012:2). The forms of disability in a population have many implications for agencies including climate change communications and education of clients, carers and communities in regard to heat, emergencies and access to adaptation resources.

The term special needs is commonly used in emergency planning as an umbrella term for people who may need special attention. Typical demographic groups included are *'people with disabilities, including people with serious mental illness; people who do not speak English or do not speak it well; children, ages 15 years and under; and people 65 years old and over'* - amounting to 49.99% of the US population. These figures do not include people living in institutions or in group homes. Other groups not included in the calculations above, but who may have special needs are: people who are morbidly obese, pregnant women, people on kidney dialysis and people living in households that do not have a motor vehicle (Kailes & Enders 2007:230-231).



Issues for people with disability and their carers

People with disabilities and their carers are one of the most disadvantaged populations in Australia (VicHealth 2012:4), making them especially vulnerable to the impacts of climate change (Polack 2008). The experience of disability follows from the *'interaction of health conditions, personal factors and environmental factors'* and varies enormously between individuals. While *'disability correlates with disadvantage, not all people with disabilities are equally disadvantaged'* (World Health Organization 2011:8). Women, people with mental or intellectual impairments or people with severe disabilities often experience greater disadvantage. People with *'wealth and status can ... overcome activity limitations and participation restrictions'* (World Health Organization 2011:8). Although we speak about people with disabilities as a population we need to remain aware that it is one with great internal variations.

In Australia, of people with disabilities 45% live in or near poverty, and have an income that is only 70% of that of a comparable person without a disability. The income of carers is a little over half that of people without the caring role (VicHealth 2012:5). People with a disability have lower levels of education, are more likely to be unemployed and to work part time than people without disabilities, and the unemployment rates are higher for disabled women than for disabled men. The majority of people with disabilities (94%) live in households (74% with other people and 20% alone). They are more likely than the population at large to own their own house a consequence of increasing prevalence of disability with age, but if they rent it can be difficult to find appropriate housing that is affordable, suitable and secure. Low income people with disabilities are twice as likely to be in public housing as people without disabilities (ABS 2010). People with disabilities are more likely than others to experience violent crime, especially women with intellectual disabilities (VicHealth 2012). These disadvantages in daily life make it more likely that people with disabilities will be socially isolated, especially if they have an intellectual disability (VicHealth 2012). Over 20% of people with disabilities access the internet (in comparison to over two thirds of non-disabled Australians) but this proportion declines for people with profound disability. The most common location of the computer is at home (ABS 2010).

The breadth and depth of social disadvantage reduces the adaptive capacity of people with disability and their carers in regard to climate change. For example, if they live in older houses income constraints are likely to make it hard to retrofit the building to conserve water and energy, and to maintain comfortable temperatures. Market based adaptation policies (such as raising prices of utilities to reduce consumption) are likely to have a disproportionate negative impact on this population.

Of the 18.5% of the Australian population with a disability in 2009 (Survey of Disability, Aging and Carers Australia 2009), over one fifth of that population required assistance (in descending order of frequency) with: 1) property maintenance; 2) cognitive/emotional issues; 3) housework; 4) mobility; 5) transport; and, 6) healthcare. The need for assistance increased with the severity of the disability.

Those with mild to moderate disability required most assistance with property maintenance and household chores while those with severe and profound disability required most assistance with core activities of mobility (72% - 88%), self care (39%-66%) and communication (13%-29%) (ABS 2010). These needs are relevant to the three climate change issues currently impacting Australians. Household maintenance is an entry point for enhanced energy efficiency and the maintenance of temperature in very hot and very cold weather. Communication, transport and personal mobility are directly relevant to emergency planning, energy consumption, response and recovery from extreme weather events. Although low income households, including those with disabled residents, consume, on average, a little less carbon than the state average, although those in outer metropolitan areas consumed more. Higher carbon consumption in outer suburbs was due to variable access to public transport, higher use of private transport and few 'high order service centres' such as health centres (Unkles & Stanley 2008).

People with disabilities often use a number of sources of assistance but 87% use informal help (typically from family members) and 59% receive help from formal providers that might be government, not for profit or for profit agencies (ABS 2010). Under conditions of climate change the sources of support become critical in emergencies. If providers of assistance leave the neighbourhood of a person receiving help, or the person with disabilities is evacuated leaving behind providers of assistance, their wellbeing and capacity to lead a dignified and independent life can be compromised.



A social justice approach to climate change and disability

The main focus of the climate change debate is on ecological and economic issues (Von Doussa 2008). Addressing physical climate change solely does not automatically improve the health and wellbeing of disadvantaged populations. Many of the policies aimed at climate change mitigation, such as reducing carbon emissions, can increase social disadvantage by imposing disproportionate costs on the population groups least able to bear them (Walpole, Rasanathan & Campbell-Lendrum 2009:799). Furthermore, *'the most vulnerable groups, by lacking a voice and influence in climate change policymaking, are unlikely to receive the support they need as policies are less likely to account for their particular experiences'* (Polack 2008:17). People whose rights are poorly protected are likely to be less able to adapt to a changing climate and social environment (Von Doussa 2008). People with disabilities and their carers are one such group. A human rights based approach to climate change directs attention to the impacts on, and actions of, people and communities. *'Who is likely to suffer what and why?'* (Von Doussa 2008:2). From a human rights perspective climate change policy making should be guided by minimum human rights standards in the assessment of competing demands on limited resources. The uneven distribution of benefits from climate change action needs to be taken

into account and the likelihood that change will exacerbate existing inequality needs to be dealt with (Human Rights and Equal Opportunity Commission 2008). In order to achieve health equity, the health sector needs to address climate stabilisation, the eradication of social disadvantage that impacts on health, and ensure health gains for the whole population (Friel et al. 2008, p. 1677). The social justice approach is about *'minimizing climate risks and enhancing adaptive capacity, whether delivered through adaptation projects or programs or climate change resilient development'* (Polack 2008:18).

Under the broad social justice umbrella there are two distinct approaches that help us to think concretely about action to meet the needs of people with disabilities and their carers. Ruger (2004) distinguishes between Rawl's theory of justice and Sen's theory of capability. Under Rawl's approach *'justice requires a fair distribution of primary goods'*. Primary goods are allocated to individuals based on *'fair equality of opportunity'* taking into account disadvantages they have accrued (Ruger 2004:1092). The policy response is to implement policies *'aimed at equalizing individual life opportunities, such as investment in basic education, affordable housing, income security and other forms of anti-poverty policy'*



(Ruger 2004:1092) that support full participation of people with disabilities in community life. Policies may be manifest in law, for example equal opportunity law, or by developing an ethical approach embodied in institutional norms and practices that support equal opportunity. Because it is extraordinarily difficult to codify the impacts of climate change in law the ethical approach is more practical (Cameron 2011:2). Initiatives that *'...[treat] climate change as a threat to human rights in a moral sense ... can draw attention to the effects of climate change on particular communities, highlight the particular causes of their vulnerability, and prompt more urgent*

ambitious responses from the states with the responsibility and capacity to act' (Cameron 2011: 3). Provision of carbon tax compensation and energy conservation interventions for disadvantaged population groups are examples of this approach in climate change policy.

In contrast, Sen's capability theory focuses on *'expanding human capabilities'* as an end in itself and as a means to gaining other valued ends. From this perspective justice *'requires improvement of the conditions under which individuals are free to choose healthier life strategies and conditions for themselves and for future generations. A capability perspective emphasizes the empowerment of individuals to be active agents of change in their own terms – both at the individual and collective level'* (Ruger 2004:1094). When the *'capabilities of people with disabilities can be expanded; their wellbeing, agency, and freedom improved; and their human rights realized'* (World Health Organization 2011:13). The ethical approach to justice requires institutions to create environments that enhance the capability of people with disabilities. For people with disabilities environments extend to include accessible built environments and transport, signage and communications for people with sensory impairments, policies and practices that make services such as health, education and employment accessible, changing knowledge and attitudes that exclude or diminish the self esteem of people with disabilities (World Health Organization 2011). The Brotherhood of St Laurence, an institution with a broad mandate to advocate for disadvantaged people, frames groups disadvantaged by climate change using population characteristics and social circumstances.

From their perspective disadvantaged groups include those: living in poverty or on low incomes; homeless or living in rental or substandard housing; older people and/or those living with disability or chronic illness; people who are socially isolated or living alone; people with limited transport mobility; children; Indigenous people; refugees and newly arrived migrants; and, unemployed people (Johnson 2012: 5). Because people with disabilities share many of these characteristics and circumstances it suggests that initiatives that address the needs of the diverse population of people with disabilities will also provide support to other segments of the community. This situation supports the idea of mainstreaming many, but not all, initiatives to address needs of people with disabilities through the strategy of universal design. Universal design refers to a practice of actively designing inclusive products, programs, services and environments so that the entire community is able to access them without the need for specialised adaptation.

Climate change action, Johnson (2012:4) argues, should be created on principles of equity, environmental effectiveness and economic efficiency, and:

- *'Target those most vulnerable to negative impacts of climate change and climate change policy;*
- *Build the capacity of those least able to adapt to a changing climate;*
- *Improve social equity and increase the inclusion of the most socially excluded.'*

Within existing policy areas governments needs to:

- *'better integrate social, climate change adaptation and disaster preparedness policy;*
- *address the immediate impacts of climate change, such as heat waves and energy costs;*
- *consider longer term implications of climate change for natural and social systems'* (Johnson 2012:6).

The two key additional climate change relevant policy areas for disadvantaged populations are:

- housing improvements by: strengthening regulations for rental properties; providing

incentives for landlords to improve rental housing stock; and, retrofitting established housing stock. There is a high proportion of home owners in the population of disabled people due to the increasing rate of disability with age. For this population support for retrofitting may be appropriate. For renters in the disability population a high proportion are in public housing. They benefit from improvements in public housing stock. Most other people with disabilities are in private rental housing where incentives for improvements apply.

- strengthening community readiness: through householder education and support for community service organisations to develop appropriate services to meet community need; engagement of low income people in adaptation planning; supporting community service organisations and local government to develop *'community connectedness, social capital and social support within their communities'*; and, *support development of 'appropriate and affordable home and contents insurance products for low income Australians'* (Johnson 2012:7).

The capability approach is often described in the emergency management literature when people with disabilities are included in emergency planning processes, 'universal design' principles are incorporated in, for example, emergency communication, and a 'dual track' (sometimes called twin track) approach to recovery is used. A dual track approach includes accessible mainstream communication, facilities and services to meet basic needs and services provided by specialist disability organisations to meet specialist needs. 'Dual track' approaches require partnership relationships between emergency responders and organisations serving people with disability.

There are human rights issues in the approaches communities take to emergency planning and response. People with disabilities and their carers may encounter problems, in emergency situations, such as: *'unequal access to assistance; discrimination in aid provision; enforced relocation; sexual and gender based violence; loss of documentation; unsafe or involuntary return or resettlement; and, issues of property restitution'* (Human Rights and Equal Opportunity Commission 2008:18-19). Disasters also disproportionately affect already disadvantaged groups. Response efforts not recognising this increases their vulnerability. Disaster response, recovery and reconstruction should embody a normative human rights based approach (Human Rights and Equal Opportunity Commission 2008:20-21).



A functional approach to emergencies and disability

The climate change issue that has attracted most discussion in the research and grey literature is extreme weather events (and other emergencies) and their implications for people with disabilities and their carers. Such events are relatively common and life threatening, some research on people with disabilities and their issues has been published, and overseas non-government organisations have made it a priority issue (for example, National Council on Disability 2006; National Organization on Disability 2009).

Reasons disability organisations are concerned about emergencies

A consortium of international disability organisations summarised a shared perspective on the experience people with disabilities have in emergencies. *'Persons with disabilities are often literally and programmatically "invisible" in the emergency response. They are excluded from or unable to access mainstream assistance programs as a result of attitudinal, physical, environmental and social barriers; they are often forgotten in the establishment of services specifically targeted for vulnerable groups; they are at risk of worsening their impairment or developing others due to lack of access to appropriate food, non-food items, health services etc. which may even be the cause of death'* (DPI, Handicap International, IDDC et al, no date:2).

A systematic literature review of research and grey literature on the Asian Tsunami and Hurricane Katrina reached a similar conclusion. It showed that *'disabled people are at greater risk of injury, mortality, disease, destitution and displacement*

when compared with the general population. While new injuries also swell the disabled population' (Hemingway & Priestly 2006: 60). There is no data on the proportion of people with disabilities in the Hurricane Katrina related deaths but there is indirect evidence. Of the deaths due to Hurricane Katrina 73% were of people over 60 years of age when that group comprised 15% of the population (National Council on Disability 2009:3). Disability rates increase with age in a population. In Australia we know that disability rates increase from 3.4% for people 4 years and under, to 40% of the population 65-69 years, and to 88% for those over 90 years (ABS 2010). The Hurricane Katrina figures are strongly suggestive of disability being a contributing factor to the deaths of people over 60 years. The barriers to survival and relief following emergencies reflect the barriers experienced by disabled people in everyday life (Hemingway & Priestly 2006: 60). No documents describing the mortality rates of people with disabilities in Australian emergencies have been found. In their absence we are left to suspect that a situation similar to that in the US exists here.

Two surveys of emergency planning personnel in the US found little evidence of awareness of, or preparation for meeting the needs of people with disabilities in emergencies. In one study no agencies had policies or guidelines designed to meet the needs of people with mobility impairments. All informants said they used the same policies to deal with everyone (they were not referring to universal design). Rural emergency personnel relied on advice from members of informal networks of people with disabilities to decide how they could be helped. Urban informants did not even know how many people with mobility impairments lived in their catchments. All informants expressed willingness to include people with disabilities in future planning but did not know how to do so (Rowland et al 2007).

A second study surveyed emergency planners in 30 US counties that had experienced disasters in the past 5 years to assess their preparedness for meeting the needs of people with disabilities. Only 6.9% of counties made changes post disaster to better meet the needs of people with disabilities and 60% of the changes were made in response to federal mandates, only 29% of changes were based on learning from the disaster. Only 13% of counties included people with disabilities in planning. Of county emergency managers 57% did not know how many people with mobility impairments lived in their county. Of those who did 'know' most made broad estimates based on unreliable data or best guesses. Only 20% of counties had disaster guidelines for people with disabilities and operating procedures to follow the guidelines. The reasons for not having

guidelines were cost and lack of trained personnel. Seventeen percent of counties said that public education was required before they would make guidelines for people with disabilities a priority and 25% would only do it if required by State level authorities (Fox et al 2007). People responsible for emergency planning were not focused on the needs of people with disabilities.

No Australian documents summarising the status of people with disabilities in emergency plans and planning have been found. But an online key word search, using the term 'people with disabilities', of a small number of Emergency Management Australia documents, found that in some documents there were no hits and in others the discussion was about populations with special needs, including people with disabilities, and was very general. In the absence of Australian evidence we should suspect that Australian emergency planners are similar to their American counterparts.



A function-based approach to disability and emergencies

Disaster planning needs to move away from lists of 'vulnerable persons', that is persons with impairments, to 'vulnerable situations' that people move in and out of over time (Fjord & Manderson 2009:67). From this point of view an emergency is one in which the environment has changed to such a degree that the resources a person with a disability uses may no longer be adequate to meet his or her needs.

People with disabilities can be considered those with one or more activity limitations, such as 'reduced capacity or inability to see, lift, walk, speak, hear, learn, understand, remember, manipulate or reach controls, and/or respond quickly' (Kailes & Enders 2007:233). Viewing disability in this way leads to the inclusion of people with functional limitations not normally labeled as having a disability – including people with heart disease, respiratory disease, emotional or psychiatric conditions, arthritis, asthma, for example. It can also include temporary limitations on function resulting from, for example, accidents, injuries (sprains, broken bones), pregnancy and people with functional limitations due to the disaster itself (Kailes & Enders 2007). *'In disaster management activities, it is important to think broadly about disability in terms of function and not in terms of an impairment or diagnosis. Traditional narrow definitions of disability are not appropriate'* (Kailes & Enders 2007:233). The emphasis in emergency planning should be on meeting function based needs (National Organization on Disability 2009).

Inclusive planning to meet functional needs of diverse populations is the most efficient and effective approach to disaster planning.

'Adequately addressing functional support needs has a far greater impact on how well individuals survive than any specific diagnosisBy planning for people with functional needs, an operational set of predictable supports can be developed. A functional support framework provides for commonalities in planning among a large array of impairment types. This framework provides a way to operationalize support for functional needs and activity limitations that may be the same, even though the impairments may be very diverse' (Kailes & Enders 2007: 233).

A function-based framework for emergency planning has the following characteristics (National Organization on Disability 2009):

1. Communication is accessible to people who cannot see, hear or understand traditional communications including people whose English is limited. Communication refers to 'languages, display of text, Braille, tactile communication, large print, accessible multi-media as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology' (United Nations 2007).
2. Diverse medical needs are planned for including unstable medical conditions, infectious conditions, treatments and life support equipment.

3. Planning assumes the maintenance of survivors' functional independence. Maintenance of support networks is critical for the continuity of independent living of people with disabilities. If an emergency disrupts the social networks a disabled person may end up in inappropriate residential accommodation (Priestley & Hemingway 2006:29). Early screening for functional needs allows them to be met, if necessary through specialist disability organizations. This enables people, to '*maintain health, mobility and functional independence, as well as manage in mass shelters*' (Kailes & Enders 2007: 235).
4. Planning takes into account the needs of some people for supervision. A variety of reasons may lead to some people having difficulty functioning in a new or stressful environment. It may include some individuals with, for example, dementia, severe depression, schizophrenia, intellectual disability, prisoners and unaccompanied children.
5. Diverse transportation needs are included in planning. These needs include wheelchair accessible vehicles, affordable transport for people with little money, people who cannot drive for any reason, and so on.

Interagency partnerships are critical for good disaster planning. Organisations that specialize in the provision of services to disabled people need to be involved in disaster planning, preparedness, response, recovery and prevention activities. Local disability services are likely to respond differently, but more effectively, than many main stream services (Hemingway & Priestley 2006).

The role of disability organizations in emergency planning and response is to:

Identify those in the community who might have functional needs before, during, and after a disaster or emergency.

Customize awareness and preparedness messages and materials for specific groups of people and put them in alternative and accessible formats, thereby increasing the ability of these individuals to plan and survive in the event of an emergency.

Educate citizens with disabilities about realistic expectations of service during and after an emergency, even while demonstrating a serious commitment to their functional needs.

Learn and gain from the knowledge, experiences, and non-traditional resources the disability community can bring to a partnership effort with emergency professionals.

Work with institutional and industry-specific groups that are not typically considered emergency service resources but that can offer valuable and timely support to emergency professionals (National Organization on Disability (2009:23-24).

Inclusive mainstream emergency planning should:

- Provide services that are inclusive and accessible to people with functional limitations;
- Employ some people with functional limitations in appropriate emergency roles (to capitalize on their knowledge and relationships with their communities);
- Develop partnerships with community based disability organizations (CBOs) who are connected to and trusted by their communities;
- Include community based organisations in disaster planning and response and develop agreements to include their strengths and skills in plans;
- Include a functional support coordinator in emergency shelters and recovery centres;
- Include screening questions in emergency shelter and recovery centre intake registration processes;
- Train emergency people in issues of functional need (Kailes & Enders 2007: 236).

Universal design principles are an affordable way of increasing access to services, information and infrastructure. Universal design means: *'the design of products, environments, programs and services usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. Universal design shall not exclude assistive devices for particular groups of persons with disabilities where this is needed'* (United Nations 2007). The application of universal design can be critical for emergency evacuation of buildings and can enable communications during evacuations if new technologies are available that help people with sensory and cognitive impairments to keep informed (WHO 2011:184). Disabled people's organization are advocating for universal design including in computers and the web to facilitate communications for people with diverse impairments (WHO 2011:191).

The Principles of Universal design are the following. Further details can be found on the WA Disability Services Commission website.

- Equitable use
- Flexibility in use
- Simple and intuitive use
- Perceptible information
- Tolerance for error
- Low physical effort
- Size and space for approach and use (WA Disability Services Commission 2008 http://www.disability.wa.gov.au/aud/planningbetteraccess/universaldesign/principles_of_universal_design.html)



Issues for people with disabilities in emergencies

Major issues for people with disabilities during emergencies are not always captured in the statistics. The experience of disability provides a deeper understanding of issues and required actions. A focus on experience leads to questions such as:

- *'What is it like to be a person with a disability during and after an emergency?'*
- *Can one hear or understand the warnings?*
- *Can one quickly exit a home or workplace?*
- *Can one move about the community after evacuating?*
- *Are there necessary or even vital daily items (medicines, power supplies, medical devices) that are not likely to be available in emergency shelters?*
- *Are basic services, like rest rooms and showers, available and accessible to people with disabilities?*
- *Does the person require assistance from a caregiver?' (National Organization on Disability 2009:17).*

To address these questions emergency planners need to analyze needs and form meaningful partnerships with the disability organisations (National Organization on Disability 2009:17).

Below are categories of issues that create difficulties for people with disabilities and their carers in emergencies. Typically these issues are reported by disability organizations that have been involved in emergency response, in collating post disaster evidence, or who report the limited research that is available.

1. **General issues:** Movement and access to documentation is difficult; people become vulnerable to physical, sexual and emotional abuse specially women and children with disabilities; isolated people left behind have difficulty contacting tracing programs.
2. **Evacuation in an emergency:** Issues include: inaccessible escape routes, loss of assistive technology; people providing physical assistance flee leaving disabled people behind; or, carers stay disrupting families. When social networks of disabled people are disrupted during an evacuation impacts people in many ways including their access to shelter, food, water, and services for people with disabilities. Where data has been collected it shows that disabled people's lives were put adversely at risk, not simply by individual limitations but by social and environmental factors. These included the '*vulnerability of buildings and facilities used by disabled people, an absence of specific evacuation plans, inaccessible warning information, lack of accessible evacuation transport, failure of backup systems [including power failures] and sometimes, the actions of neighbours, staff and rescue workers*' (Hemingway & Priestley 2006: 61). Furthermore, '*emergency planning should include criteria for recognizing the various*

forms of evacuations and for evaluating a proper response' (Christensen, Blair and Holt 2007:252).

3. **Information.** Because data on people with disabilities in communities is poor people with disabilities are not included in registration systems. Furthermore, disaster relief personnel are poorly informed of options for people with disabilities. Communications are often inaccessible for people with sensory impairment (White 2006).
4. **Food aid and nutrition.** People with disabilities experience: barriers to accessing food distribution points; long wait times; no special diets for people with special dietary needs; difficulty carrying home food rations; food for work schemes that discriminate.
5. **Water and sanitation.** People with disabilities experience difficulty collecting and carrying water and inaccessible toilet and bath areas.
6. **Inaccessibility of shelter.** People most likely to experience accessibility problems in accessing shelter were wheelchair users, and '*people with visual, hearing and cognitive impairment*' (Hemingway & Priestley 2006: 61). Sometimes disabled people were turned away from relief camps and encouraged to access specialist services which were not always able to respond appropriately. There are often few options for temporary accessible housing post emergency (Rooney & White 2007).
7. **Access to health care.** People with disabilities experience disruption to regular services and encounter services unable to meet disability related needs.

8. *Livelihood.* People with disabilities experience loss of special tools needed to earn a living and obstacles to accessing new livelihood activities. They have problems returning to daily routines due to post disaster emotional trauma, lack of mobility and problems with the affordability and accessibility of temporary housing (Rooney & White 2007:209).

9. *Participation.* People with disabilities also experience systematic exclusion from evaluations, assessments, interviews, community committees and leadership roles, thus reinforcing discrimination (DPI, Handicap International, IDDC et al, no date; Hemingway & Priestley 2006: 61).



Three key themes emerged from a symposium on planning for vulnerable communities in an emergency: risk communication, evacuation procedures and continuity of services (Gilbert et al 2009). Below the findings from a review of the experiences of people with disabilities and their carers during Hurricanes Katrina and Rita in the US are summarised as a way of providing a practical perspective on key issues. Details from other research has also been included where appropriate.

Risk communication

An evaluation of general health promotion materials for people with disabilities (Williams-Piehotá et al 2010) found that the major sources of information in the United States were health care providers, the internet, friends and family, and print materials. A service type not identified in this study, but one we know is most likely to be trusted by people with disabilities, is disability service providers. In the absence of evidence to the contrary we should assume that these are also likely sources of health promotion information in Australia and to be appropriate sources of information on climate change and human health and wellbeing. The study authors recommend that the disability audiences be segmented by functional need, materials be tailored to each audience, language be simple and direct, materials delivered in multimodal format, materials be pre-tested several times during development, and preferred communication channels used. Critically, people with disabilities needed to be involved in the production of materials (Williams-Piehotá 2010).

Emergency alerts and communication.

Pre-hurricane warnings in the US were accessible to most people via TV. Emergency warnings when the hurricanes struck were often inaccessible to people with sensory impairments due to

the absence of sign interpreters or other communication aids. This is also a problem in every-day life. *'As barriers to the daily use of information and telecommunications technology decrease, so will the barriers to emergency communication'* (National Council on Disability 2006:4). People with hearing impairments could not comprehend evacuation instructions or other instructions in shelters. People with visual impairments could not comprehend TV information because audio descriptions of visual displays of maps or lists of affected areas were not provided. People who tried to use alternative communications such as cell phones were unable to access information when infrastructure failed. Radio was the only remaining communication technology but that failed people with hearing disability. It is recommended that daily media routinely adopt *'standardized methods, systems and services to identify, filter and present content in ways that are meaningful to people with disabilities leading up to, during and after emergencies'* (National Council on Disability 2006:6). Furthermore, a wide variety of media should be used for emergency information. The principles of universal design should inform risk communication to ensure that communications are accessible to as many people as possible (Gilbert et al 2009).

Evacuation procedures

Christensen, Blair and Holt (2007) classify evacuations into four categories each with different implications for people with disabilities. They are **1) protective evacuations** (long term pre-impact responses to emergency situations eg individual precautionary evacuation); **2) preventive evacuations** (short term pre-impact responses eg a bomb threat requiring movement to another part of a building); **3) rescue evacuation** (short term, immediately post impact evacuation eg evacuating a burning building); and, **4) reconstructive evacuations** – (long term, post impact in the context of ‘impaired health and safety’ eg moving evacuees to camps or temporary housing). Overlying these categories of evacuation are individual behaviors, planned evacuation systems and the environment in which the evacuation is occurring. The implications of behavior, planned systems and environment differ depending on the type of evacuation. For example whereas a person with a disability may be able to act appropriately in long term evacuations, this may not be possible in a short term one due to their need for time to negotiate obstacles, or sheltering in place for people with disabilities eg in a protected stair well to await assistance from an emergency responder, may be appropriate for a preventive evacuation, but be inappropriate for a rescue evacuation. In general reliance on planned systems for evacuation leaves people with disabilities vulnerable. More attention needs to be given to the built systems to reduce obstacles to evacuation.

Emergency transportation.

Many people with disabilities were unable to evacuate because transport was inaccessible either in its location or design. Without some form of registration it is difficult to locate people with disabilities in an emergency in order to provide transport. Registration that includes home addresses can be found with some disability service provider organizations, private or municipal, but they may not be shared with emergency responders (Takahashi et al 1997). The transportation barriers (related to Hurricane Katrina) were ‘*magnified versions of daily barriers to accessible transportation*’ (National Council on Disability 2006:8). Either planners had not considered the needs of people with disabilities or their arrangements did not work because they had not consulted people with disabilities to arrive at realistic options. Successful hurricane evacuation plans included:

- Additional planning pickup routes
- Extra time to load and unload evacuation vehicles
- Appropriate resources eg buses with wheelchair lifts
- Plans that clearly articulated methods for evacuating people with disabilities including the roles of schools, emergency managers and transport agencies
- Encouraged voluntary registration of people with disabilities
- Practiced evacuation plans

Emergency mass shelter and food. Some initial challenges faced by people with disabilities are inherent to any disaster response eg confusion, shortage of trained people. However many of the most significant problems could have been addressed with inclusive planning. Some people were refused entry to shelters and others could not access shelter services eg medical care, restrooms, food, communication and transport services. People with intellectual disabilities found shelter environments difficult (Takahashi et al 1997). People with disabilities who live independently in the community should be able to access general shelters. The most successful general shelters were not run by emergency personnel but by local people who practiced inclusiveness.

Continuity of services

For people with disabilities livable communities include:

- *Affordable, appropriate housing*
- *Accessible, affordable, reliable, safe transportation*
- *Physical environment adjusted for inclusiveness and accessibility*
- *Work, volunteer and education opportunities*
- *Access to key health and support services*
- *Access to civic, cultural, social and recreational activities'* (National Council on Disability 2006:17).

These are the issues requiring continuity of service.

Housing. Accessible and affordable short term and long term housing was very difficult to find. Reconstruction did not typically address the issues of accessibility or indeed of livable communities.

Employment. Provision of employment is a key to recovery. Even prior to the hurricanes employment for people with disabilities was a problem.

Education. Returning to school is key for children. For children with disabilities accessing their required supports in new schools may be a problem. Schools planning to receive children with disabilities is a major help.

Healthcare. Many shelters had no or few medical supplies. Inclusion of links to hospitals in planning helped in this regard.

The National Council on Disability (2006:23) recommended that as a starting point local communities and municipalities:

- establish voluntary self registries of people with disabilities
- include people with disabilities in planning at all levels
- ensure coordination of emergency plans
- develop a communication plan to inform people with disabilities about emergency plans
- establish an office or person with sole responsibility for disability issues.

Fox et al (2007), based on a study of emergency responses in the United States, would expand these local level actions to include:

- Strengthen training for local level emergency managers.
- Raise awareness of people with disabilities of need for personal and community level disaster planning.
- Include people with disabilities as trainers.
- Integrate emergency planning systems with health care providers and community based organizations.
- Improve surveillance systems to identify people with disabilities in the region using registries and list of people known to disability organisations.
- Develop warning systems using multiple communication technologies.
- Work with disability organizations to promote personal disaster planning.

Rooney and White (2007) identified the following set of self-help actions people with mobility impairments can take to improve their survival chances in an emergency.

- Preparation that included general supplies, disability-related supplies, equipment and medication
- Evacuation plans, preregistration of emergency assistance and disaster preparedness training

- Useful items to have after evacuation included food, water, generators, cash, specialized mobility or medical equipment
- Preplanning that included self-assessments of risks, capacity to respond, emergency needs supplies and equipment.
- Building support networks of co-workers, family and friends that could provide assistance. The most highly rated support services in emergencies are: family, friends, neighbours, followed by police.

In the recovery period post-emergency it is common for case management systems to be used to assist people with complex needs. Case management for people with disabilities needs to be qualitatively different from that with non-disabled people. It is more intense and with more contacts, is of longer duration, and more complex. The complexity of the cases requires case managers to have expertise in the disability service area (Stough et al 2010). People with disabilities share issues such as housing, transport and long recovery time with non-disabled people. However, the barriers for people with disabilities were much greater making recovery particularly difficult for many people with disabilities (Stough et al 2010).

Conclusion

People with disabilities will almost certainly experience heightened disadvantage as climate change impacts strengthen and communities need to make increasingly substantial adaptations. Extreme weather events are the impact of climate change currently causing distress for populations across Australia, and is the one area where a small amount of research has been undertaken to understand the experience of people with disabilities. To address the needs of people with disabilities a social justice approach to climate change adaptation in general is needed. It also requires that mainstream emergency planning becomes more inclusive. Disability organisations have a role in aiding the adaptation of people with disabilities as well as working with mainstream emergency organisations to develop a dual track approach to emergency planning and response.



Bibliography

The Bonn Declaration (2007) Declaration from the international Conference 'Disasters are always inclusive: Persons with disabilities in humanitarian emergency situations'. November 2007, Bonn.

Australian Bureau of Statistics (2010) Disability, ageing and carers, Australia: Summary of findings, 2009. ABS, Canberra.

Australian Bureau of Statistics (2011) Census dictionary, 2011. ABS, Canberra.

Bethel JW, Foreman AN and Burke SC (2011) 'Disaster preparedness among medically vulnerable populations'. American Journal of Preventive Medicine. 40(2):139-143.

Costello et al (2009) 'Managing the health effects of climate change'. The Lancet. 373:1693-1733.

Christensen KM, Blair ME, Holt JM (2007) 'The built environment, evacuations, and individuals with disabilities: A guiding framework for disaster policy and preparation'. Journal of Disability Policy Studies. 17(4):249-254.

Department of Human Services (2007) Climate change and health: An exploration of challenges for public health in Victoria. Department of Human Services, Melbourne.

DPI, Handicap International, IDDC et al (no date) For a UNHCR Executive Committee Conclusion on Disability. Joint submission. No publication details given.

Fjord L and Manderson L (2009) 'Anthropological perspectives on disasters and disability: An introduction' Human Organization. 68(1):64-72.

Fox MH, White GW, Rooney C and Rowland JL (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(4):196-205.

Friel, S, Marmot, M, McMichael, AJ, Kjellstrom, T & Vagero, D (2008), 'Global health equity and climate stabilisation: a common agenda', The Lancet, vol. 372, no. 9650, pp. 1677-1683.

Frumkin H, Hess J, Iubler G, Malilay J and McGeehan M (2008) 'Climate change: The public health response'. American Journal of Public Health. 98(3):435-445.

Garnaut, R. (2008) The Garnaut climate change review: Final report. Cambridge University Press, Port Melbourne.

Hemingway L and Priestley M (2006) 'Natural hazards, human vulnerability and disabling societies: A disaster for disabled people'. The Review of Disability Studies. 11(3):57-68.

Horton, G., McMichael, T. and Doctors for the Environment (2008) Climate Change health check 2020. The Climate Institute, Sydney.

Huang C, Vaneckova p, Wand X, Fitzgerald G, Guo Y and Tong S (2011) 'Constraints and barriers to public health adaptation to climate change: A review of the literature'. American Journal of Preventive Medicine. 40(2):183-190.

Human Rights and Equal Opportunity Commission (2008) Human rights and climate change: Background paper. HREOC, Sydney.

Johnson V (2012) Barriers to effective climate change adaptation: Submission to the Productivity Commission Inquiry. Brotherhood of St Laurence, Melbourne.

Kailes JI and Enders A (2007) 'Moving beyond "special needs"'. A function based framework for emergency management and planning'. Journal of Disability Policy Studies. 17(4):230-237.



National Council on Disability (2006) The impact of hurricanes Katrina and Rita on people with disabilities: A look back and remaining challenges. National Council on Disability, Washington DC.

National Organization on Disability (2009) Emergency preparedness initiative: Guide on the special needs of people with disabilities for emergency managers, planners and responders. Revised edition. NOD, Washington DC.

Polack E (2008) 'A right to adaptation: Securing the participation of marginalized groups'. *IDS Bulletin*. 39(4):16-22.

Priestley M and Hemingway L (2006) 'Disability and disaster recovery: A tale of two cities'. *Journal of Social Work in Disability & Rehabilitation*. 5(3-4):23-42.

Rooney C and White GW (2007) 'Narrative analysis of disaster preparedness and emergency response survey from persons with mobility impairments'. *Journal of Disability Policy Studies*. 17(4):206-215.

Rowland JL, White GW, Fox MH and Rooney C (2007) Emergency response training practices for people with disabilities: Analysis of some current practices and recommendations for future training programs'. *Journal of Disability Policy Studies*. 17(4):216-222.

- Ruger JP (2004)** 'Ethics of the social determinants of health'. *The Lancet*. 364(Sept 18th):1092-1097
- Russell R.C., Currie B.J., Lindsay M.D., Mackenzie J.S., Ritchie J.S. and Whelan P. (2009)** 'Dengue and climate change in Australia: predictions for the future should incorporate knowledge from the past'. *Medical Journal of Australia* (190(5):265-268.
- Stough LM, Sharp AN, Decker C and Wilker N (2010)** 'Disaster case management and individuals with disabilities'. *Rehabilitation Psychology*. 55(3):211-220.
- Takahashi A, Watanabe K, Oshima M, Shimada H and Ozawa A (1997)** 'The effect of the disaster caused by the great Hanshin earthquake on people with intellectual disability'. *Journal of Intellectual Disability Research*. 41(2):193-196.
- The Global Partnership for Disability & Development (GPDD) and The World Bank (Human Development Network – Social Protection/Disability & Development Team) (2009)** *The Impact of Climate Change on People with Disabilities*. GPDD and The World Bank.
- United Nations General Assembly (2007)** *Convention on the Rights of Persons with Disabilities: resolution*. United Nations, Geneva.
- United Nations (2007)** *Convention on the rights of persons with disabilities*. United Nations, Geneva.
- Unkles B and Stanley J (2008)** 'Carbon use in poor Victorian households by local government area'. *Brotherhood of St Laurence*, Melbourne.
- Uscher-Pines et al (2009)** 'Disaster preparedness of households with special needs in southeastern Pennsylvania'. *American Journal of Preventive Medicine*. 37(3):227-230.
- VicHealth (2012)** *Disability and health inequalities in Australia: Research summary*. VicHealth, Melbourne.
- Von Doussa J (2008)** 'Climate change and human rights'. *Insight*. June.
- Walker R, Hassall J, Chaplin S, Congues J, Bajayo R and SEHCP (2011)** 'Health promotion interventions to address climate change: A literature review'. *Health Promotion Journal of Australia*. 22(special issue):S6-S12.
- Walker, R. and South East Healthy Community Partnership (2009)** 'Climate Change and Primary Health Care Intervention Framework' *Australian Journal of Primary Health* 15(4):276-284.
- Walpole, S, Rasanathan, K., & Campbell-Lendrum, D. (2009)** 'Natural and unnatural synergies: climate change policy and health equity'. *World Health Organization. Bulletin of the World Health Organization*, Vol. 87, Issue 10, pp. 799-801.
- Williams-Piehota P, Uhrig J, Doto JK, Anderson W, Williams P and Thierry JM (2010)** 'An evaluation of health communication materials for individuals with disabilities developed by three state disability and health programs'. *Disability and Health Journal*. 3(3):146-154.
- World Health Organization (2011)** *World Report on Disability*. WHO, Geneva.
- White B (2006)** 'Disaster relief for deaf persons: Lessons from Hurricanes Katrina and Rita'. *The Review of Disability Studies*. 11(3):49-56.
- WHO (2008)** *World Health Report 2008: Primary health care – Now more than ever*. World health Organization, Geneva.
- WHO and UNICEF (1978)** *Declaration of Alma Ata*. International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September
- Wolbring G (2009)** 'A culture of neglect: Climate discourse and disabled people'. *Media Culture Journal*. 12(4):no pages given.

Appendix 1.

Literature searches

Search on climate change and disability

1. Academic literature (14/8/2012)

Search terms:

1) 'climate change OR global warming OR greenhouse effect' and 2) 'disability OR people with disabilities'

Selection criteria:

1) published between 2000 – 2012, addressed both climate change and disability, 2) full text available, 3) published in an academic journal.

Databases:

Proquest central	0 results
Cinahl	1 results
Emerald	0 results
Medline	0 results
Expanded academic	0 results

In some searches a significant number of papers were located but they were about climate change and made only passing reference to people with disabilities as a disadvantaged group but did not discuss the issues for them.



2. Grey literature - NGOs

Selection criterion: discussed disability and climate change or an aspect of climate change.

Search of websites of major disability organisations:

National Council on Disability (USA)
International Disability and Development Consortium (IDDC)
Handicap International
World Vision
Nobody Left Behind (USA)
United States Federal Emergency Management Agency
Red Cross (USA)
World Health Organization
United Nations
Global Partnership for Disability and Development

Search of other relevant websites:

Australian Human Rights and Equal Opportunity Commission
VicHealth

3. Bibliographies of published papers.

4. Journals likely to publish on either the climate change and health field eg *The Lancet*, or on Disability eg *Journal of Disability Policy Studies*, looking for papers in which the two fields are combined.

5. Disability research centres –publications lists

Leonard Cheshire Disability and Inclusive Development Centre



Appendix 2:

Rationale for the engagement of community based organisations with climate change

The health and social care organisations participating in Primary Care Partnerships in Victoria can collectively be described as a local primary health care system. The organisations have diverse mandates, and provide diverse services, as they undertake activities consistent with their mandate. As members of the primary health care system they share similar positions within the structure of society (such as concern with people in local communities and first points of contact for those people) and share a number of guiding principles (such as accessibility and equity). There are variations in the definitions of primary health care in use but the enduring one is contained in the Declaration of Alma Ata (1978). The Declaration of Alma Ata was a product of collaboration between the World Health Organization (WHO) and the United Nations International Children's Emergency Fund (UNICEF). A more detailed discussion of primary health care can be found in Definition of Comprehensive Primary Health Care - Appendix 2.

Primary health care is defined in the Declaration of Alma Ata (WHO and UNICEF 1978) as:

Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made

universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process

More recently it was argued in the World Health Report (WHO 2008) that there are a number of developments, reflecting core primary health care principles, shared by primary health care systems around the world. These are apparent at the point of convergence between: *"the evidence on what is needed for an effective response to the health challenges of today's world, the values of equity, solidarity and social justice that drive the primary health care movement, and the growing expectations of the population in modernizing societies"* (WHO 2008:xvi).

These developments are intended to ensure that:

- *that health systems contribute to health equity, social justice and the end of exclusion, primarily by moving towards universal access and social health protection – universal coverage reforms;*
- *reforms that reorganize health services as primary care, i.e. around people's needs and expectations, so as to make them more socially relevant and more responsive to the changing world while producing better outcomes – service delivery reforms;*
- *reforms that secure healthier communities, by integrating public health actions with primary care and by pursuing healthy public policies across sectors – public policy reforms;*
- *reforms that replace disproportionate reliance on command and control on one hand, and laissez-faire disengagement of the state on the other, by the inclusive, participatory, negotiation-based leadership required by the complexity of contemporary health systems – leadership reforms (WHO 2008:xvi).*

These changes, happening in many countries, should be reflected in the primary health care system's response to climate change impacts on the Australian population.

A health system policy response to climate change must be based on an integrated approach that has three levels of action: organisation, household and individual action to reduce carbon emissions; organisation, household and individual actions to reduce the impacts of climate change through adaptation to a changing environment; and, an

appropriate service system that can deal with adverse health outcomes from climate change across the continuum of care (Walker and SEHCP 2009; Walker et al 2011). The rationale for primary health care services and systems to address the climate change relevant needs of people with disabilities and their carers is embedded in the concept of primary health care.

In primary health care mitigation is typically about reducing energy consumption in organisations, households and communities. Adaptation is about adjusting services (such as providing assistance to vulnerable people with heat wave planning) and enabling adaptation of clients and communities through health promotion. A useful definition of adaptation, used in public health, is '*any short or long-term strategies that can reduce adverse health impacts or enhance resilience in response to observed or expected changes in climate and associated extremes*' (Huang et al 2011:184).

Adaptation can be about building adaptive capacity by increasing the '*the set of resources available for adaptation as well as the ability to use them effectively and efficiently*' (Huang et al 2011:184), for example increasing provision of appropriate climate adapted housing plus increasing accessibility to it for people with disabilities. Adaptation can also be about implementing adaptive actions, for example personal emergency planning.

Frumkin et al (2008) argue that the principles of medical ethics are applicable to health sector engagement with climate change. '*Medical ethics are usually based on four principles: autonomy, beneficence, nonmaleficence and justice.*

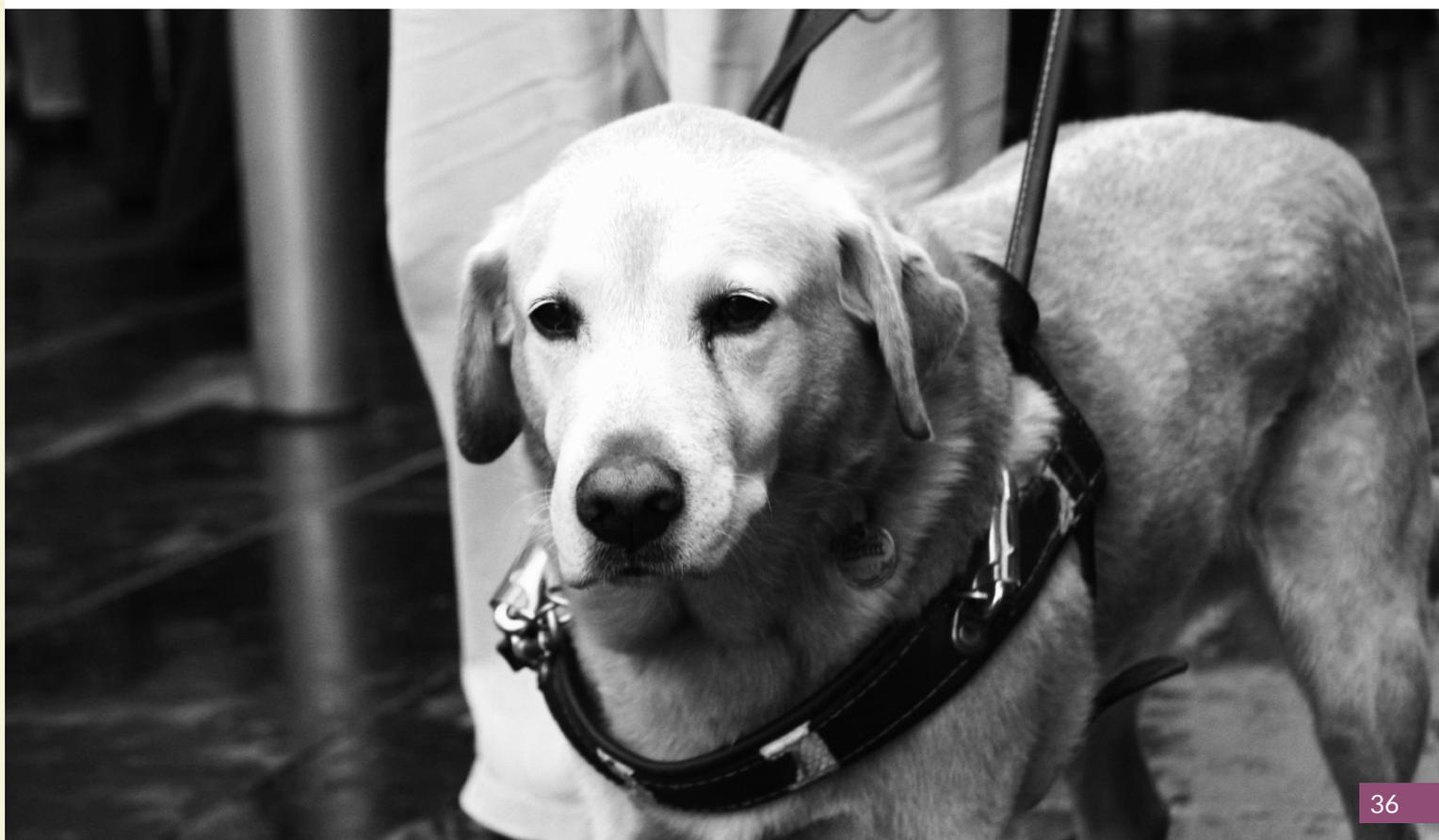
Addressing climate change embodies beneficence because it protects people now and in the future, and nonmaleficence because it avoids harms (including distant 'downstream' harms) that flow from climate change. Justice considerations arise in the inequities that characterise the impacts of climate change and the ability to cope with them' (Frumkin et al 2008:437). Autonomy may be expressed through encouragement of personal responsibility for climate change risk reduction in the context of organizational and community level risk reduction efforts.

When developing adaptation initiatives relevant to people with disabilities and their carers it is necessary to incorporate their point of view, addressing their needs, experiences and expectations. A compelling reason for doing so, as expressed by Wolbring (2009) in relation to emergencies, is that *'[d]isabled people are differently affected in all phases of a disaster,*

from exposure to risk and risk perception; to preparedness behavior, warning communication and response; physical, psychological, social and economic impacts; emergency response; and ultimately to recovery and reconstruction' (Wolbring 2009:3). It is also necessary to ensure that mainstream adaptation efforts are inclusive of people with disabilities.

The Declaration of Alma Ata identifies some core principles underpinning primary health care. They are;

1. Health is a human right
2. Gross inequality in the health status of population groups is unacceptable. Health equity is at the core of a health system.
3. Economic and social development is required for the attainment of health for all.
4. People have a right and a duty to participate individually and collectively in the planning and implementation of their health care.



Article VII of the declaration of Alma Ata describes the elements of primary health care. In the table below these have been aligned with a potential primary health care response to climate change.

Table 1. The 7 key Activities of Primary Health Care, with Climate Change Examples.

Article VII Declaration of Alma Ata (WHO & UNICEF 1978)	Primary health care response to climate change
1. <i>Reflects and evolves from the economic conditions and socio-cultural and political characteristics of the country and its communities and is based on the application of the relevant results of social, biomedical and health services research and public health experience.</i>	Primary health care responds to the national, state and local policies, social and economic conditions as they intersect with the effects of climate change in local communities. It uses the best evidence available in developing interventions. Interventions may involve participating in national programs (eg energy efficiency) or developing initiatives specific to a locality (eg planning for the health effects of local fires or floods or to address the needs of specific population groups in that locality).
2. <i>Addresses the main health problems in the community, providing promotive, preventive, curative and rehabilitative services accordingly.</i>	Services will participate in climate change mitigation activities relevant to their local community. They will cope with, and adapt to, the impacts of climate change in their community and on the people they serve. This may involve change in service provision across the continuum of care as well as in the operation of the organisation (eg energy efficiency).
3. <i>Includes at least: education concerning prevailing health problems and the methods of preventing and controlling them; promotion of food supply and proper nutrition; an adequate supply of safe water and basic sanitation; maternal and child health care, including family planning; immunization against the major infectious diseases; prevention and control of locally endemic diseases; appropriate treatment of common diseases and injuries; and provision of essential drugs.</i>	At a minimum it will include: health promotion activities in regard to mitigation, adaptation and coping; food and water safety in hot weather and after natural disasters such as floods; hydration of vulnerable people in hot weather; prevention of mosquito, water and food borne infectious diseases; and the provision of basic health services in times of natural disaster. Successful action on most of these issues requires close collaboration with public health services.
4. <i>Involves, in addition to the health sector, all related sectors and aspects of national and community development, in particular agriculture, animal husbandry, food, industry, education, housing, public works, communications and other sectors; and demands the coordinated efforts of all those Sectors.</i>	It works in partnership with other sectors on climate change mitigation, adaptation and coping initiatives.
5. <i>Requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate.</i>	Through its activities it strengthens individual and community resilience. At an individual level this is through person centred service provision and at a community level through facilitation of community competence, social capital, and good communication with the community. Resilience of communities is a characteristic that enhances capacity to adapt and cope with change and stressful events. Inclusiveness is a core value.
6. <i>Should be sustained by integrated, functional and mutually supportive referral systems, leading to the progressive improvement of comprehensive health care for all, and giving priority to those most in need.</i>	Mitigation and adaptation initiatives are integrated to meet the needs of clients/patients and the special needs of vulnerable population groups. Equity is a core value in decision making.
7. <i>Relies, at local and referral levels, on health workers, including physicians, nurses, midwives, auxiliaries and community workers as applicable, as well as traditional practitioners as needed, suitably trained socially and technically to work as a health team and to respond to the expressed health needs of the community.</i>	Mitigation and adaptation initiatives are integrated into the daily work of multidisciplinary health care teams.

Public health and primary health care share many values and concerns but differ in the services they provide. Whereas public health tends to focus on preventive services that impact on populations (eg immunisation), primary health care provides diverse services to individuals and families, to improve individual and community health, and on the promotion of health in communities. Although the central concerns of primary health care and public health are different there are also many areas where they intersect and strong partnerships would strengthen the community's response to climate change. In the table below Frumkin et al (2008) have mapped climate change issues on to the essential public health services as defined by the United States Department of Health and Human Services.

Table 2. *The 10 Essential Services of Public Health, with Climate Change Examples (Frumkin et al 2008:438).*

Service	Climate Change Example
1. Monitor health status to identify and solve community health problems.	Tracking of diseases and trends related to climate change.
2. Diagnose and investigate health problems and health hazards in the community.	Investigation of infectious, water-, food-, and vector-borne disease outbreaks.
3. Inform, educate and empower people about health issues.	Informing the public and policymakers about health impacts of climate change.
4. Mobilize community partnerships and action to identify and solve health problems.	Public health partnerships with industry, other professional groups, faith communities, and others, to craft and implement solutions.
5. Develop policies and plans that support individual and community health efforts.	Municipal heat-wave preparedness plans.
6. Enforce laws and regulations that protect health and ensure safety.	(Little role for public health).
7. Link people to needed personal health services and ensure the provision of health care when otherwise unavailable.	Health care service provision following disasters.
8. Ensure competent public and personal health care workforce.	Training of health care providers on health aspects of climate change.
9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services.	Program assessment of preparedness efforts such as heat-wave plans.
10. Research for new insights and innovative solutions to health problems.	Research on health effects of climate change, including innovative techniques such as modelling, and research on optimal adaptation strategies.

References

Frumkin H, Hess J, Iuber G, Malilay J and McGeehan M (2008) 'Climate change: The public health response'. *American Journal of Public Health*. 98(3):435-445.

WHO (2008) *World Health Report 2008: Primary health care – Now more than ever*. World Health Organization, Geneva.

WHO and UNICEF (1978) *Declaration of Alma Ata*. International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September