Disability and Disaster Risk Reduction / Emergency Preparedness
Scoping Review

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Disability and Disaster Risk Reduction / Emergency Preparedness

Background

Including people with disability in disaster risk reduction (DRR) policy, planning and implementation is a relatively new phenomenon worldwide. The international disaster risk reduction framework, the *Sendai Framework for Disaster Risk Reduction (SFDRR) 2015 – 2030* underpinned by the rights framework of the *UN Convention on the Rights of Persons with Disabilities (CRPD)*, United Nations, 2006) provides impetus for further development in this field.

The *World Report on Disability* (WHO, 2010) reported that 15% of the world’s population lives with disability. People with disability are known to be more vulnerable in the face of a natural hazard emergency. There is now evidence to suggest that people with disability are two to four times more likely to die or be injured during natural disasters than the general population (UN Office for Disaster Risk Reduction [UNISDR], 2013). They are also less likely to receive aid and ongoing support to recover over the longer term. Risk for people with disability is further increased when systems are fragmented and the responsibility for people with particular needs and capabilities is unclear.

This paper presents a scoping review of the scientific literature undertaken as part of the *Disability Inclusive Disaster Preparedness in NSW: Enabling Local Community Resilience Through Collaboration* project. This project was funded under the Community Resilience Innovation Program (2014-2015), Office of Emergency Management, NSW Department of Justice. This program is part of the NSW and Commonwealth governments’ National Partnership Agreement – Natural Disaster Resilience Program.

The project approach brought together community service organisations for people with disability, people with disability, other community organisations and agencies and personnel from emergency management agencies to build community capacity that includes people with disability. Within the context of this project, this scoping review presents an overview of the state of knowledge about people with disability and disaster risk reduction contained in the scientific literature. Prior to the findings of this review, we provide an overview of the relevant international and national frameworks and definitions and concepts used in the field of disability inclusive disaster risk reduction (DiDRR).

International frameworks

The relevant international framework for disaster risk reduction is the *Sendai Framework for Disaster Risk Reduction (SFDRR) 2015 - 2030*. This is the first international framework in which disability is specifically mentioned. Prior to this as

Disability was first acknowledged by the international DRR community in 2012 in a regional document, the Yogyakarta Declaration. This Declaration was produced as an outcome of the 5th Asian Ministerial Conference on Disaster Risk Reduction (AMCDRR) that occurred as part of regional HFA consultations. The declaration specifically noted the importance of the active participation of at-risk communities as follows:

“....to ensure the active contribution of risk-prone communities, particularly persons with disabilities, women, children and the elderly, and to meet their different needs...” (UNISDR, 2012, p.2)

The UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) is the first comprehensive, international framework devoted to disability. Article 11 of this Convention obligates State Parties to ‘take 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’. Other articles in the CRPD are also relevant to DRR. Article 9 specifies that people with disability have a right to equally access the physical environment, transportation and communication technologies and systems. In a disaster context this right includes equal access to warning systems, evacuation plans or emergency shelters. Further, Article 29 requires that people with disability must be included in planning, policy development and implementation in any matters that affect their lives. This requires actively including people with disability in DRR activities and emergency preparedness policy, planning and implementation.

Regional frameworks

In Asia and the Pacific region, the most recent regional framework, Make the Right Real. The Incheon Strategy for Persons with Disabilities in Asia and the Pacific 2012-2020 has a clear focus on disability inclusive disaster risk reduction (DiDRR). This framework recognizes the particular vulnerability of this region to natural disasters and, building on CRPD, takes a rights based approach to implementing DiDRR. Goal 7 is Ensure disability inclusive disaster risk reduction and management. This is further specified in two targets accompanied by core and supplementary indicators. The two targets are as follows. Target 7.A Strengthen disability-inclusive disaster risk reduction planning. Target 7.B Strengthen implementation of measures on providing timely and appropriate support to persons with disabilities in responding to disasters. This regional focus on DiDRR is an important step towards realising the rights of persons with disability as required by the CRPD.
National frameworks

Australia has a National Strategy for Disaster Resilience (COAG, 2011) agreed by the Council of Australian Governments in February 2011. This framework is built on the concept of shared responsibility to create community resilience and thereby reduce risk in the face of natural hazard emergencies and disasters. The concept of shared responsibility includes the role of the federal government, state and territory governments, and local government, and the role of business, non-government organisations and volunteers, and individuals in each and every community. The strategy document is accompanied by the National Strategy for Disaster Resilience Companion Booklet (Commonwealth of Australia, 2012) which contains seven priority areas including: (1) leading change and coordinating effort; (2) understanding risks; (3) communicating with and educating people about risks; (4) partnering with those who affect change; (5) empowering communities to exercise choice and take responsibility; (6) reducing risks in the built environment; and (7) supporting capabilities for disaster resilience. Illustrated case studies accompany each priority area for action.

The high-level governance arrangements for overseeing the implementation of the Australian framework include the Standing Council on Police and Emergency Management (SCPEM). SCPEM has six key responsibilities – one of which is the provision of national leadership on emergency management and disaster resilience. There is no mention of disability in the National Strategy for Disaster Resilience. In the National Strategy for Disaster Resilience Companion Booklet people with disability receive mention as a group that requires special attention by SCPEM, as do other groups considered to be at additional risk including indigenous people.

Disaster risk reduction: definition and concepts

According to the UN Office for Disaster Risk Reduction (UNISDR), DRR is defined as the concept and practice of reducing disaster risks through systematic efforts to analyse and manage the causal factors of disasters, including through reduced exposure to hazards, lessened vulnerability of people and property, wise management of land and the environment, and improved preparedness for adverse events (https://www.unisdr.org/we/inform/terminology).

DRR approaches consider the scale of a disaster in terms of impact on the population, on housing and on livelihood and public services rather than the severity of the event. DRR encompasses a broad range of activities that target the causal factors of disaster to lessen disaster impact. DRR policy and practices aim to combine the best available knowledge of natural hazards and associated risks. From a population perspective the question is: “what factors can be controlled or influenced to limit the human impact from a natural hazard and associated disaster event? Emergency or disaster preparedness are terms more often used in the community or public information approaches to communicate awareness and the need for individuals and communities to be involved, prepared and to build resilience to face natural hazard emergencies. Emergency preparedness is often described in ways such as the following that comes from the US Center for Disease Control and Prevention and Disease and focuses more specifically on health emergencies:
‘Many people are concerned about the possibility of a public health emergency such as a natural disaster, act of terrorism, or disease outbreak. You can take steps now to help you prepare for an emergency and cope if an emergency happens’.

(https://emergency.cdc.gov/preparedness/)

Disaster preparedness is frequently used in Australia for example by organisations such as Australian Red Cross to raise awareness of the need for individuals and communities to be adequately prepared:

‘Being prepared for a bushfire, cyclone, flood or whatever emergency may come your way means you’re more likely to cope and get your life back on track’.

(http://www.redcross.org.au/prepare.aspx)

In this scoping review the terms emergency preparedness and disaster risk reduction are used in this dual sense of preparedness for individuals and for communities.

**Purpose of the scoping review**

This scoping review set out to address the following question: What do we know about reducing disaster risk and increasing emergency preparedness for people with disability?

The aim of a scoping review is to ‘scope’ the parameters of the field of study rather than to provide a detailed analysis of the state of knowledge. Scoping reviews are frequently carried out where there is a newly emerging field, typically with few theoretical and empirical underpinnings. As Mays, Roberts and Popay (2001) noted scoping studies “aim to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, can be undertaken as stand-alone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before” (p.194). Thus, scoping reviews aim to locate the major writings in the field without aiming to obtain a comprehensive data base of all available scientific publications, position papers, policy documents, program descriptions and evaluations and so on (Arksey & Malley, 2005; Gough, Oliver & Thomas, 2012; Levac, Colquhoun & O’Brien, 2010).

The advantage of scoping reviews undertaken in an emerging field such as disaster risk reduction for people with disabilities is the capacity to highlight initiatives from around the world as these are reported. Papers are often prepared for example in response to implementation of international frameworks or particular events or circumstances that give rise to new concerns or considerations. Both of these reasons are apparent here. In the first instance the coming into force of the UNCRPD in 2006 and the relatively rapid signing and ratifying by member nations of this international human rights convention. Second, there has been strong advocacy
internationally and in Asia and the Pacific by the Disability Inclusive Disaster Risk Reduction Network (DiDRRN) to include people with disability as first occurred in the Yogyakarta Declaration in 2012, followed by their inclusion in the SFDRR in 2015. And third, impetus for new initiatives has come from the large scale natural disasters in the United States including Hurricane Katrina and Typhoon Sandy and the Great East Japan Earthquake and Tsunami where for the first time data became available on the number of PWD who died or were injured.

Given this rapidly emerging field of DRR and emergency preparedness for people with disability, we set out to provide a scoping review of the scientific literature on this topic. We initially also explored the grey literature via relevant websites of organisations engaged with persons with disability such as CBM International, Handicap International, and the Centre for Disability and Development in Bangladesh and those engaged with DRR such as UNISDR. Projects reported on these websites and reference lists were hand searched for reference lists of key papers. In doing so, it quickly became clear that due to the variety of terms used and project specific terminology, ‘locked’ access requiring membership to obtain reports or papers, languages other than English, and instability of URLs, scoping this literature was not possible. Rather, a grey literature review needed to be undertaken as a separate and comprehensive stand-alone project beyond the time and resources available in the current project.

Instead we refer the reader to a recent and up-to-date compilation of grey literature in this field of DiDRR hosted by Ask Source (http://www.asksource.info/). In this disability and development repository there is a section on DiDRR activities and projects in the context of international development at http://www.asksource.info/topics/humanitarian/disability-inclusive-drr. This is a welcome new development. Since its inception the resources referenced on this website have expanded exponentially. These resources are a mix of position papers, case studies, reviews, UN documents and research study reports. This website provides an excellent portal for those interested in non-peer-reviewed documents and a useful proxy at this time for a more comprehensive and systematic search of the grey literature.

**Method**

**Search strategy**

A systematic search of scientific journal databases was conducted in April 2014 then updated in March 2015 and complemented at that time by a new search of an additional 8 databases. The databases and keywords used in each search are included in Appendix 1. The results of each search were exported to an EndNote Library and duplicates removed after all search results compiled. The titles and abstracts of the remaining papers were screened against the following exclusion criteria. Papers were excluded if they were:

- published before 2000,
review phase

search results

The first search undertaken in March 2014 returned over 800 papers (n=805). After duplicates and excluded papers were removed one hundred and seven papers were retained for screening. A further 64 papers were obtained from the updated search of Medline, Sociological Abstracts, Scopus and Web of Science in May 2015. The new searches of the 8 additional databases (Embase, Premedline, Cinahl, APA FT, Environmental Abstracts, Geobase, Compendex, and GreenFILE) added a further 231 papers. After screening the total 502 papers using the exclusion criteria above, 88 papers were considered relevant for this scoping review. Five papers identified through snowballing and hand searching were also added making a total of 93 papers included in the pre-analysis and coding phase.

pre-analysis and coding phase

In the pre-analysis and coding phase, four coding frameworks were developed following review of all abstracts. The first framework was related to country of location of the paper. Papers were divided into North America and other countries. This was based on understanding of the recent efforts in North America and particularly the United States of the Federal Emergency Management Agency (https://www.fema.gov/) in relation to people with disabilities in natural hazard emergencies (https://www.fema.gov/office-disability-integration-and-coordination).

The second coding framework related to type of paper and methods employed based on the diversity of approaches in this newly emerging field. The third framework developed at this pre-analysis phase was in relation to preparedness and response. Although the primary aim of the review was to scope papers addressing preparedness, it became apparent that many papers also addressed response as part of their preparedness topic and some papers combined discussion of both preparedness and response.

During this phase, one paper was identified as not meeting the inclusion criteria and thus excluded. A further seven papers were also excluded as these did not include abstracts in the exported file from the database and we were unable to locate the full...
These exclusions resulted in a final number of 85 papers included in this scoping review. Of these the majority (n=55) came from North America; the remaining 30 papers were from other countries.

**Definitions for coding frameworks**

**Paper type by method**

- Descriptive: papers that provide description of activities or programs; not empirical studies
- Literature review papers: papers that provide a narrative or systematic review of the relevant literature
- Secondary analysis: analysis of existing data sets such as population surveys, administrative data bases or data sets from previous research studies.
- Interview studies: papers that report empirical research using interview methods
- Survey studies: papers that report empirical research using survey methods
- Intervention studies: papers that report evaluation of preparedness interventions

**Preparedness or response phase**

Preparedness was defined according to the UNISDR description as follows: “The knowledge and capacities developed by governments, professional response and recovery organizations, communities and individuals to effectively anticipate, respond to, and recover from, the impacts of likely, imminent or current hazard events or conditions” ([https://www.unisdr.org/we/inform/terminology](https://www.unisdr.org/we/inform/terminology)). The papers coded with ‘preparedness’ use this term or refer to a broad number of activities that contribute to preparedness e.g. evacuation planning, identifying and engaging vulnerable groups in needs analysis, stockpiling supplies or medications. Papers coded with preparedness also include those that report on planning for disasters. Papers that report learning about preparedness from a disaster were coded as ‘response’.

Response was defined according to the UNISDR description as follows: “The provision of emergency services and public assistance during or immediately after a disaster in order to save lives, reduce health impacts, ensure public safety and meet the basic subsistence needs of the people affected” ([https://www.unisdr.org/we/inform/terminology](https://www.unisdr.org/we/inform/terminology)). Papers coded with response reported on analysis or review of the response phase including learning about preparedness from a disaster as noted above under Preparedness.

A number of papers reported on both preparedness and response and were coded accordingly in a joint category of preparedness and response.
Analysis and synthesis phases

All 85 papers were coded using the four coding frameworks. There were two analysis phases. First, numerical analysis was undertaken on the 85 papers according to the first three coding frameworks; country location of paper, paper type or method, and preparedness, response or both. Then all 85 papers were coded using the fourth coding framework on population of interest to identify the papers that addressed disability specifically. The second phase involved a thematic analysis of the 45 papers that were coded as addressing disability and preparedness to meet the requirements of the research question. (Papers addressing disability within vulnerable populations and papers addressing response were therefore excluded from this thematic analysis). Synthesis of this material was then undertaken to provide discussion on the current state of knowledge in this emerging field of DI/DRR/emergency preparedness and potential ways forward.

Findings

The findings are presented first in matrix format using the coding frameworks to capture country location, paper type by method, and preparedness or response or combination of both. The overarching country location framework is used to differentiate between North America and other countries. This was considered an important distinction given that the context of a high-income country such as the United States is significantly different from papers addressing this topic in low and middle-income countries. The findings from the thematic analysis are then presented.

Numerical analysis

A numerical analysis was conducted of the type of paper and preparedness or response. This is presented in Figure 1. Over half of the papers (n=55) came from the North American context. Findings from this numerical analysis show that almost half of papers (n=40) across both North America (n=19) and other countries (n=21) are descriptive. That is, these papers describe the issues for people with disability in disaster situations and/ or programs and approaches applied in response to these issues. This finding is not surprising given the early stage of development of research knowledge about people with disability in natural hazard and disaster situations. In the early stages of field development, papers describing the issue or problem dominate (Llewellyn et al., 2014 at http://sydney.edu.au/health-sciences/cdrp/projects/auditresearch.shtml). As a field of study matures, empirical papers that seek to answer specific questions or test interventions begin to appear.

Most of the papers focused on preparedness (North America n=40; other countries n=12) or both preparedness and response (North America n=3; other countries n=8). A total of 22 papers (North America n=12; other countries n=10) were coded as response only and therefore excluded from the thematic analysis.
In terms of the fourth coding framework on disability and vulnerability a total of 17 papers (North America n=10; other countries n=7) were coded as papers that discussed vulnerability more broadly and included people with disability as one of several groups of people who are more at risk during a disaster. These also were excluded from the thematic analysis. This left a remaining 45 papers that had a disability focus and were relevant to preparedness for thematic analysis.

Figure 1 presents the numerical analysis by methodology (paper type) of the papers located and the phase of disaster (preparedness, response or both preparedness and response) they address. To reflect the large amount of research conducted in North America the papers have been grouped in two categories of country location: North America and all other countries.

**Thematic analysis**

Thematic analysis of empirical research papers (n=45) was guided by the research question underpinning this scoping review: *What do we know about reducing disaster risk and increasing emergency preparedness for people with disability?*

The themes derived from our analysis are presented in this section. The themes are: *degree of preparedness of people with disability; organizational responses to including people with disability in preparedness activities; and community preparedness including people with disability.*

The overwhelming majority of the empirical research papers come from studies conducted in North America. The most frequent type of research method utilised was survey, North America papers n=20, other countries n=3; followed by interview, North America papers n=6, other countries n=4; intervention, North America papers n=5, other countries nil; literature review, North America papers n=1, other countries n=2; secondary analysis North America papers n=4, other countries nil.
Preparedness of Individuals with disability and household preparedness

The majority of papers in this section come from the US. The primary focus is on assessing the personal or household preparedness of people with disability and discussing how preparedness could be increased at the individual or household level. Several papers have used surveys to assess the preparedness of people with disability or their families. For example, Sakashita, Matthews & Yamamoto (2013) evaluated the preparedness of a convenience sample of 50 families with a child dependent on electrical medical equipment and found that most were inadequately prepared for a power failure. Gershon et al. (2013) surveyed by way of an on-line questionnaire a convenience sample of 253 people with cognitive and/or physical disabilities living in the community and all receiving personal assistance services. These authors found that when people with disability had involvement of a personal assistant in their emergency plan they scored higher overall on an emergency preparedness scale.

Another approach to assessing preparedness comes from two studies that evaluated the evacuation plans of full time wheelchair users (Hogaboom, Oyster, Riggins & Boninger, 2013; McClure et al., 2011). Hogaboom et al. (2013) conducted telephone interviews with a convenience sample of 21 people with spinal cord injury living in the community. McClure et al. (2011) surveyed a convenience sample of 487 people with spinal cord injury who use a wheelchair more than 40 hours a week and located via six Spinal Cord Injury Model Centers. Both studies found that while most of the respondents indicated they would be able to evacuate in an emergency the majority did not have an evacuation plan or they had a plan that had not considered all potential scenarios.

Only one paper outside the US context examined individual preparedness in a similar manner to that of the US papers mentioned above. In this study by Tomio et al. (2012) the authors assessed by survey the preparedness of over 500 (n=553) participants from a nationwide patient group of over 1000 people with rheumatoid arthritis in Japan. Only one-half had taken medical preparedness measures and only one-quarter had taken general preparedness measures. They concluded that overall, preparedness measures taken by the participants was insufficient. As the study did not compare the preparedness scores of the participants with that of the general population it is not clear whether this insufficient preparedness would also be found more broadly than this specific group of people.

Preparedness of people with disability compared to the general population

The studies above rely on within-group methods to assess individual preparedness. That is, they examine the preparedness of a particular group of people, in this case people with disability. Missing from this method is data that would permit understanding of the preparedness of people with disability in relation to the general population. Ideally this would also include information on geographical location, capacity as well as functional limitations, and inter-connectedness (or otherwise) with local community and social networks. This information is critically important for policy and planning purposes.
Five studies were located which assessed disaster preparedness of people with disability (and often including people with poor health and chronic diseases compared to the general population. These studies typically use survey or secondary analysis of existing administrative data sets to understand behavioural intentions. (Bethel, Foreman & Burke, 2010; Smith & Notaro, 2009; Uscher-Pines et al., 2009). For example, Bethel et al. (2010) examined the association of general health status, disability status, and chronic disease status, respectively, with disaster preparedness, among Behavioral Risk Factor Surveillance System (BRFSS) survey respondents. Vulnerable populations were generally less likely to have household preparedness items but more likely to have medication supplies than their counterparts. Using data from the 2006-2007 Behavioral Risk Factor Surveillance System of 6 states that included 188,288 self-reported respondents with disabilities Smith and Notaro (2009) found that persons with a disability are 1.22 times more likely to be unprepared for an emergency. For those with a disability, being female, nonwhite, with less education, less income, and uncoupled and living in an urban area this increases the likelihood of being unprepared for an emergency.

These findings suggest that when authors compare the emergency preparedness of people with disability to the population as a whole, people with disability score lower on preparedness scales than the general population without disability. However, the findings are mixed using this method. For example, Uscher-Pines et al. (2009) conducted a random-digit-dial telephone survey with 501 adults in southeastern Pennsylvania in 2008. The survey instrument gathered data on socio-demographic characteristics, disability status/functional limitations, and preparedness behaviors related to an evacuation emergency. The authors reported that no significant differences were identified with respect to awareness of evacuation routes, purchasing of food and water, or creation of an emergency plan to guide evacuation decision-making. Indicators such as arranging a place to meet, having identified a shelter or packed a bag, people with disability were consistently around twice as likely to have done so that then general population.

It is also helpful for policy and planning purposes to understand similarities and differences between sub-groups in a population experiencing a similar situation. Spence et al. (2007) study investigated, in the aftermath of Hurricane Katrina, whether there was a difference in preparedness, information seeking behaviour and media use between evacuees with and without disability. Their survey of 554 evacuees temporarily located in other areas of the United States found that people with disability were more likely to prepare for a crisis by stockpiling food, medication, emergency supplies and so on however they were less likely to plan for an evacuation.

**Interventions for improving individual or household preparedness**

As noted in the early stages of an emerging field few reports of interventions are available. We located only four papers that reported on preparedness interventions emanating from two separate research studies. Baker and Baker (2010) first surveyed a convenience sample of 145 families of children presenting to tertiary care centres about their preparedness and reported significant under-preparedness. Baker and colleagues then evaluated an education program for a convenience sample of randomly assigned families with children with special health care needs
and delivered by community health care professionals aiming at increasing their household preparedness. Using a pre and post survey design these authors and their colleagues found a statistically significant increase in preparedness as a result of the training 30-35 days post intervention including when families were located in different geographical regions (Baker & Cormier, 2013; Baker, Baker & Flagg, 2012).

Hooper (2010) reported the findings from a pilot program in Washington State that sought to use community networks to improve preparedness among people with disability. The program developed a curriculum for building preparedness and response skills in people with disability. The train the trainer model involved training disability advocates to deliver the curriculum to people with disability in their community. However, despite its apparent success, the author reports that the curriculum was not adopted by government agencies as an ongoing program. The author concluded that the concept of disability inclusiveness is still in its infancy in the field of emergency management, which lacks sophistication in addressing issues for people with disabilities in emergency preparedness and response policy and planning decisions.

The last intervention located employed a peer-to-peer intervention for young adults with intellectual disability living independently in the community. Eisenman et al. (2014) reported on a study in which adults were randomly assigned to an experimental arm or a wait-list control arm with pre-and post-testing. Four two-hour classes co-taught by a health educator and peer-mentors focused on earthquake safety knowledge and preparedness supplies. Improvements in preparedness were maintained at 1-month post-intervention. Interventions such as this align with more recent approaches to DRR and emergency preparedness which emphasise the critical importance of including those most at risk such as people with disabilities in learning from and teaching each other.

The second theme addresses how organisations consider people with disabilities in their preparedness activities.

**Organisational responses to including people with disabilities in preparedness activities**

The papers grouped in this theme report on the measures organisations have taken to prepare for a disaster such as developing evacuation plans and designing communication and alert systems. These papers specifically focus on the inclusion of disability in these activities.

**Organisational responses: is disability on the agenda?**

Writing from the UK context, Twigg (2014) analysed vulnerability and capacity assessments often used to understand the vulnerability within particular geographic or social communities. The author found that while the stated purpose of these assessments is to identify and understand what makes members of a community vulnerable at the time of disaster, identifying people with disability are often overlooked. Of the 28 assessments reviewed, 15 did not mention disability and only two engaged with the social exclusion of people with disability. As Stough and Kang (2015) noted this is in contrast to the SFDRR that explicitly mentions people with
Organisational responses: schools

Inclusive response measures can be implemented in diverse institutional contexts in the community. A series of Australian papers addresses the preparedness of Australian schools to offer appropriate protective measures and inclusive responses for children with disability. This series of papers comes from a team at James Cook University led by Professor Helen Boon. The papers are described in some detail as these come from the local context and are currently the most fulsome in the literature with regard to specific institutional responses. Boon et al. (2011) published a critical literature review of the literature on the preparedness of schools for responding to disaster or emergency and protecting children with disabilities in their care. The authors searched four major scientific databases relevant to disability and education research. Their searches returned 1,080 papers of which 10 met the criteria for full manuscript review. All of the 10 papers were US studies. The authors found from these 10 papers that although most schools had engaged in disaster planning there were significant gaps in preparedness efforts for accommodating the needs of children with disabilities. The gaps included mobility or communication needs of children with disability during evacuation procedures or connecting with local health authorities to ensure specific health needs could be accommodated during the response phase. The authors also noted the small amount of empirical evidence available for schools to use when framing and developing policy in this area of disaster risk preparedness for school children with disability.

Two further papers from Boon and her colleagues built on this literature review. The first paper presented the results of an analysis of the publicly available policies, guidelines and frameworks used for disaster planning in Australian schools for disability inclusiveness. The results demonstrated that inconsistencies in definitions and terminology around vulnerability, special needs and disability could impact on the inclusion of children with disabilities in other policies such as those for disasters and emergencies. The authors noted the possibility that some groups will be overlooked for example children who function independently on a daily basis but may have an underlying condition that places them at greater risk during an emergency. They also identified that while students with disabilities usually have an individualised care plan for day to day, usually these have not considered their needs in an emergency situation. The specific requirements of students with mental health needs during and after an emergency were also discussed noting that current plans and documents for mental health needs of students do not consider emergency situations. In sum the authors suggest that at risk students must be identified during the planning phase with information relevant to emergency situations included in their individualised plans. Coordination with local support services such as the ambulance service was also considered critical.

In the second of the two papers reporting their follow up study Boon, Brown and Pagliano (2014) present their findings of a survey of Australian schools about planning for students with disability in emergency. The survey was mailed to 450 government schools in Western Australia and South Australia and 80 responses were received. The survey was structured around five ‘types’ of disability
(physical/mobility impairment, chronic conditions/special needs, sensory impairments, emotional/behavioural disability, cognitive impairment) and asked about planning for each in the planning, acute and recovery phase of disaster and for different types of hazards. Seventy-seven percent of the respondent schools had experienced a disaster. Less than one third of the schools had specifically addressed the needs of students with disabilities in their disaster planning. The survey also found that most schools were not represented at the local disaster planning group. The authors conclude that further research, including qualitative studies, is needed to better understand how schools appropriately include children with disabilities in their disaster response planning.

Organisational responses: service providers

In a similar approach a group of researchers from South Carolina conducted a telephone survey with administrators from 16 agencies that provide in-home personal care to 2,147 clients, and five agencies that provide in-home health care to 2,180 clients to understand whether and how agencies involved in the provision of home care services to people with disability and elderly clients were involved in preparing their clients for disaster (Laditka et al., 2008). This qualitative study found that there was large variation in the level of preparation amongst the agencies and that in general health agencies were better prepared than personal care agencies. Better coordination with other agencies and more staff training were identified as major need for improvement by the participants.

Maja-Schultz and Swain (2012) also writing in the US context raised similar issues in a narrative literature review of the risks for people with disability living in adult care facilities (ACFs). The authors discussed the importance of services being involved in preparedness activities to build the personal preparedness of staff and clients in these facilities. Further they noted that emergency response systems need to have built in measures to accommodate the needs of their clients at time of disaster. This could include appropriate evacuation facilities and communication systems.

Organisational responses: Accessible preparedness and response measures and resources

Another group of papers have explored how organisational preparedness and response measures can be made accessible for people with disability. There are several papers from the US context that examine communication and education materials for their accessibility including for all literacy levels (Davis, 2007) and people with vision or hearing impairments (Davis, 2007; Ivey et al., 2014; Neuhauser et al., 2013). Christensen, Blair and Holt (2007) for example discussed the importance of emergency warning systems that consider the accessibility needs of people with disability. Johnson et al. (2010) reported on a framework for inclusive mobilebased alert systems. Putkovich (2013) in a recent paper assessed the national emergency warning system of the US as suitable or not for people with disability. This paper identified needs and provided recommendations for reaching members of the community with disability.
Organisational responses: Appropriately trained emergency personnel and related workforce

Organisational preparedness responses have also been examined at the level of workforce and training. This is a critically important issue in the response phase and no less in the preparedness phase for building community networks and resilience that are inclusive of people with disability. In an early paper Batscha (1997) suggested that mental health care providers must be aware of the increased risk of heat-related illness for their clients with longstanding mental illness and develop heat-wave management plans with these clients, a group of persons with disability rarely considered in DRR research.

In a paper a decade later, Rowland, White, Fox and Rooney (2007) analysed emergency personnel training practices to assist people with mobility impairments in three rural and three urban locations in Northeast Kansas for the extent to which they prepared responders to assist people with disability. They reported on the barriers and facilitators that emergency services staff identified to training specifically focusing on building skills to assist people with disability. More recently, Wolf-Fordham, Twyman and Hamad (2014) reported the results of an online training program that was developed to build knowledge for disability inclusive preparedness and response in emergency responders. Promisingly, participants improved in post-test scores after completing the training.

Two relatively recent papers have drawn attention to the role of one particular group of health professionals in disaster preparedness and response. In an editorial for the Australian Occupational Therapy Journal Sinclair (2014) discussed international health and disability and disaster risk reduction policy and their relevance for the occupational therapy profession. She concludes by stating that increasing numbers of people affected by disasters or conflict means that occupational therapists will increasingly be working within these contexts and therefore the profession must engage with translating these international policies into practice. Explaining this by way of case study from Bangladesh, Habib et al. (2013) offered a real life example of the experience and roles of occupational therapists in disaster management. In the qualitative study reported, six occupational therapists were interviewed about their experience and roles pre, during and post disasters. Their primary role pre-disaster and during disaster was to assist with training and developing inclusive responses such as inclusive shelters. Post disaster they supported counselling, rehabilitation, vocational training and home modifications/rebuilding.

Community preparedness including people with disability

Community and social networks

Another group of papers have explored the social and community factors that can contribute to vulnerability or resilience for people with disability. Bricout & Baker (2010) discussed online social networks playing a role in communicating and locating people with disability during disasters. These authors have proposed ‘an analytic model for understanding the role of distributed networks in mediating the negative impacts of a disaster or an emergency on persons with disabilities is proposed,
Disability Inclusive Disaster Preparedness in NSW: Enabling Local Community Resilience through Collaboration

together with key objectives for change’. This provides one example of a social strength that could build resilience. A survey with a convenience sample of 710 people with disability from 7 US states (Zakour, 2015) found that informal social support, voluntary memberships, and personal assistance frequency were statistically significant predictors of preparedness.

In similar vein, Tanaka (2013) writing after the Great East Japan Earthquake noted factors that led to children with disability dying in this disaster at twice the rate of the rest of the population. This led the author to stress the importance of engaging families and service workers who provide the day to day care of children with disabilities being actively engaged in all discussions about individual and household preparedness – given their familiarity with and knowledge about the particular capacities, needs and constraints for children with disabilities and their families. This finding came from the authors' analysis of responses to the disaster in which ‘those who, whether as assisters or the assisted, were involved with the disabled on a daily basis from before the disaster’. Tanaka (2013) concludes that 'raising children as part of their local communities is the biggest factor in saving them from disaster'.

Learning from experience

Priestly and Hemingway (2007) writing in the UK context analysed the recovery responses to two significant events – The Great Asian Tsunami (2004) and Hurricane Katrina (2005). Their analysis was framed by the social model of disability. Put simply, this means that disability is regarded as an outcome of societal structures and lack of accommodation for people with impairments or chronic health conditions. These authors suggested that future preparedness planning needs to move beyond individual preparedness and focus on structural measures. They found that in both disasters, although occurring in very different social, political and economic contexts, the response measures failed to meet the needs of people with disability. They also suggested that the way in which people with disability are framed as vulnerable and lacking capacity is one reason why response measures fail. This is because this approach excludes people with disability from preparedness activities. Their lived experience knowledge of disability and for many previous disasters is not taken into account.

More recently Abbott and Porter (2013) writing from the United Kingdom conducted a scoping review of the literature, reports and policy documents, conversations with relevant voluntary organisations and groups of disabled people to understand their views on the relationship between environmental hazards and disability. They set out to examine the extent to which the voices of people with disability are included only to find these voices largely absent from the literature on environmental hazards. Again, these authors suggested that the skills, knowledge and lived experience of people with disability are of great value and need to be taken into account in preparing to manage natural disasters.

Information needs about people with disability and inclusion of disability perspectives

Enders & Brandt (2007) and Kailes & Enders (2007) writing in the US context identified both the importance of disability data being included in geospatial
information systems which guide the coordination of emergency response, and the development of frameworks for understanding the functional needs of people with disability in communication, mobility, transportation, and their medical needs in a disaster scenario. Again in the US context, Webster (2014) explored the legal implications of emergency preparedness plans and the requirements that jurisdictions ensure the ability of plans, planning efforts, programs, and services to meet the needs of people with disability and others with access and functional needs. This focus is particularly relevant in the Australian context, where local government areas are now required to prepare Disability Inclusion Plans as the third level of government required to do so under the National Disability Strategy 2010-2020 as well as Emergency Preparedness Plans.

With regard to policy approaches, from the US context Fox et al. (2007) reported the findings from a survey of 30 randomly selected Federal Emergency Management Agency sites. They found that people with disability were not represented in planning activities and that only one fifth of the agencies had disability guidelines in place. Further to this, the majority had no plans for updating policies and guidelines to include people with disability. Rooney and White (2007) also reported on the information needs of people with disability during a natural disaster and how people with disability use media at those times. From an online Internet survey with a convenience sample, 56 persons with mobility impairments who have experienced a catastrophic event shared what they found helpful for survival, what was difficult, and suggestions for future planning. Overall, individual preparedness was reported as helpful however most difficulties were experienced when community or institutional preparedness had not included people with disability in their plans or response measures such as shelters were not inclusive.

As we reported in the research and policy briefs (attached) from the Department of Foreign Affairs and Trade Australian Aid Research and Development Project in Indonesia 2013-2015, building capacity within individuals, communities and organisations is critical to increasing resilience for all in the face of natural disasters. The SFDRR specifically addresses the inclusion of people with disability in preparedness and planning policies and implementation. International activities following this framework initiated by the Disability Rights Fund (http://www.disabilityrightsfund.org/) included a funding round for DiDRR. Three Disabled Persons Organisations in Indonesia were the recipients of funding under this scheme and are currently implementing their own disability led disaster risk reduction programs in two locations on Java Island and one on Sumatra (Pertiwi, 2016). However, the findings from the scoping review reported in this section suggest there is much yet to be achieved in involving people with disability in preparedness planning and implementation and importantly, in policy so that the aspiration embedded within SFDRR for disability inclusive disaster risk reduction and emergency preparedness can be realised.
Conclusion

This scoping review of the scientific literature on disaster risk reduction/ emergency preparedness for people with disability demonstrates an emerging field of study. Although people with disability have been recognised as likely to be at greater risk in natural disasters it is only recently that they have been acknowledged specifically in disaster risk reduction frameworks at the international and regional levels with specific recognition yet to come at the Australian national level. The contribution of CRPD from 2006 as the international human rights instrument about persons with disability has driven a greater interest over the past decade in including people with disability in all aspects of daily life. That said, it is as recent as 2015 when people with disability were first specifically mentioned in an international disaster risk reduction framework, SFDRR 2015-2030.

Prior to this time people with disability were seen primarily through the lens of vulnerability to the extent that the earlier literature and much that was initially sourced for this scoping review focused on individual vulnerability of people with disability and as a sub-group of vulnerable persons. With the advent of CRPD and accompanying initiatives to empower people with disability about their rights such as the Disability Rights Fund the emphasis now is on inclusion and participation of people with disability in all matters that affect their lives. Similarly, in the field of disaster risk reduction and emergency preparedness there has been a move away from a focus on vulnerability to addressing the capacities and capabilities of individuals and communities to engage in preparedness activities to enhance their resilience in the face of natural disaster events.

This scoping review demonstrates that the majority of the literature on people with disability and emergency preparedness remains primarily US based in a context of relatively highly developed emergency preparedness and warning systems. The focus, not surprisingly, therefore is on particular events and being prepared taking into account the usual population based approaches to ensuring the least possible loss of life and injury. There is a scattering of empirical reports from other countries including Australia which focus more specifically on the inclusion and participation of people with disability in planning, preparedness and policy. This approach comes directly from more recent international approaches which stress the importance of all of community responses both at the individual and the organisational level.

As noted the literature on this topic is still in its infancy. Of the 85 papers sourced only around half (45) reported on empirical studies in which investigations, either quantitative or qualitative, had been undertaken. Of these most papers addressed specific research questions using convenience samples of people with disability. Although providing a useful starting point to understanding the capacities and needs of people with disability in emergency preparedness, convenience samples contain inherent bias and the findings cannot be considered as generalisable to people with disability beyond the limits of the sample taking part in the study. A further limitation of the literature is that most studies in essence describe the ‘problem’ rather than proposing and testing solutions. This is to be expected at the current early stage of development in this field however to advance the field well designed interventions
tested with rigorous designs are now needed. This is essential to move beyond declaring a commitment to including people with disabilities in emergency preparedness and ensuring their inclusion leads to effective and efficient positive outcomes for all – people with disability, their families and carers and the communities of which they are part. It is to be hoped that in the short term more intervention endeavours are undertaken and reported to build a solid knowledge base on best practice for including people with disabilities in emergency preparedness policy, planning and implementation.
References


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Thompson, K., Every, D., Rainbird, S., Cornell, V., Smith, B., & Trigg, J. (2014). No pet or their person left behind: Increasing the disaster resilience of vulnerable groups through animal attachment, activities and networks. Animals, 4, 214-240. doi:10.3390/ani4020214


## Appendix 1 – Search terms and databases

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**Differences between April 2014 and May 2015 search**
- added mitigation, natural hazard, natural disaster, storm, and landslide
- took out keywords "emergency plan*, emergency prep*, management
END OF REPORT

The views expressed herein do not necessarily reflect the views of the NSW Government, unless the views expressed in the project materials have been publicly supported by the Government, or Government Agency.