New Zealand wheelchair users' preparedness for emergencies

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Abstract

People with disabilities are disproportionally affected by emergency situations. They experience higher mortality rates and greater vulnerability than the general population due to disrupted infrastructure and services. Although personal preparedness has been identified as one of the most effective ways to mitigate the emergency-related risks, personal preparedness among people with disabilities is reported to be low. The aim of this study was to investigate emergency preparedness of wheelchair users in New Zealand and to compare their preparedness levels with those of the general population. A nationwide survey of adult, community dwelling wheelchair users was conducted. Of 101 participants, less than 30 percent had made emergency preparations for a future emergency which is substantially lower than the rate reported among the general New Zealand population. Fewer than 20 percent of survey participants were planning for their disability specific needs. Personal preparedness barriers identified included the need for assistance from someone else to carry out planning activities (50%), lack of disability relevant information (37%), limited accessibility to information (24%), cost (23%), and being unable to stockpile medications (20%) or consumables (11%). Overall, participants reported lower levels of personal emergency preparedness and

a higher incidence of barriers to preparedness than reported by the general New Zealand population. A comprehensive plan of further work and research could enable genuinely inclusive emergency planning for future emergency events in New Zealand. To achieve this outcome, emergency planners, responders and researchers must partner with disabled people so that planning meets the emergency related needs of disabled New Zealanders.

Keywords: *emergency preparedness, wheelchair users, people with disabilities, disaster management, emergency planning*

New Zealand is an island nation whose landscape has been shaped by earthquakes, volcanic eruptions, floods and other natural events over millions of years. Many such events have had destructive social and environmental consequences throughout New Zealand's history of human habitation, triggering local or national emergencies (Officials' Committee for Domestic and External Security Coordination, 2007). Of these natural hazard events, flood is the most common type of emergency in New Zealand. In addition, around 150 earthquakes are strong enough to be felt each year, with a further ten to fifteen thousand smaller earthquakes recorded per year.

While all members of a community are exposed to the risks associated with disasters at similar rates, vulnerability is not shared equally among the population. An individual's vulnerability during disaster is influenced by socio-economic status, degree of social empowerment and access to resources that can mitigate risk or assist recovery from emergencies (United Nations, n.d.). Within this context, a range of international experience (Adams, Kaufman, van Hattum & Moody, 2011; Bethel, Foreman & Burke, 2011; Brunkard, Namulanda & Ratard, 2008; Chou et al., 2004; Doocy, Daniels, Packer, Dick & Kirsch, 2013; Fujii, 2012; Hogan et al., 2011; Markwell & Ratard, 2008; Ramirez & Peek-Asa, 2005; United Nations, n.d.; White, Fox, Rooney & Cahill, 2007) has shown that the elderly and people with disabilities are at greater risk of further disablement, injury or death in emergency situations, compared to the general population.

In 2013, people with disabilities represented nearly a quarter of the New Zealand population with over one million people having at least one disability (Statistics New Zealand, 2014a). Physical impairment resulting in mobility issues was the most common disability reported as at 2013, affecting 13 percent of the general population (557,000 individuals) (Statistics New Zealand, 2014b). The New Zealand age-adjusted disability profile demonstrates there is a slightly higher rate of disability for Māori (32%) and Pacific people (26%) compared to New Zealand European (24%) people. Asian populations had the lowest rate of age-adjusted disability, at only 17 percent. Higher rates of disability among Māori may worsen other socio economic difficulties faced by the indigenous populations of New Zealand. This is because people with disabilities in NZ tend to have poorer outcomes across a range of social and economic factors than the non-disabled population. They are more likely to live alone, reside in areas of greater deprivation, be unemployed and have lower personal and household incomes (Office for Disability Issues, 2013; Statistics New Zealand, 2014c).

Personal preparedness has been identified as one of the most effective ways to mitigate risks associated with emergencies (Levac, Toal-Sullivan & O'Sullivan, 2012; Smith & Notaro, 2015) and is a core aspect of emergency planning for New Zealand (Ministry of Civil Defence & Emergency Management, 2010). Community members are generally encouraged to ensure they can be self-sufficient for at least three days. This includes stockpiling and maintaining a supply of food, water and other emergency survival items, having a survival plan which includes what to do both at home and away, and having a plan for contacting family or other significant people (Levac et al., 2012; Ministry of Civil Defence & Emergency Management, 2010). People with disabilities are additionally encouraged to consider evacuation route planning, stockpiling consumable products and medications, making arrangements with carers and support networks and alternative options for essential equipment (Federal Emergency Management Agency, 2015; Ministry of Civil Defence & Emergency Management, n.d.; National Organization on Disability, 2009).

Personal preparedness among people with disabilities is reported to be relatively low in developed western countries (Gershon, Kraus, Raveis, Sherman & Kailes, 2013; National Organization on Disability, 2005; Smith & Notaro, 2009; Smith & Notaro, 2015; Wolf-Fordham, Curtin, Maslin, Bandini & Hamad, 2015). Research by McClure et al. (2011) identified a sharp division between United States wheelchair users with spinal injuries who felt they could safely evacuate their homes (85%) and those who had managed to formulate a feasible evacuation plan (64%). Although issues underlying such poor levels of preparedness are generally under-researched, they are likely to include: a lack of disability-accessible information; the cost of setting up an emergency survival kit; an inability to stockpile consumable items especially medications; relying on others to assist with making preparations, or; for some socially isolated individuals, making and maintaining support networks (Riscoe, Schlegelmilch & Paturas, 2013).

Emergency preparedness and planning remain important issues for people with disabilities due to their increased vulnerability to disasters and other emergencies. Brereton (2012), Dunn, Nicholls, Cassidy and Sinnott (n.d.), Phibbs, Good, Severinsen, Woodbury and Williamson (2014; 2015), Phibbs, Woodbury, Williamson and Good (2012) have nonetheless noted that there has been little research into levels of preparedness among disabled New Zealanders. The aim of this current study is to address this lack of research, by investigating emergency preparedness among wheelchair users in New Zealand and comparing their levels of preparedness with preparedness in the general population.

Methods

A survey was developed through an iterative process. Multiple drafts were developed following guidelines for writing on-line survey questions and designing on-line surveys, by Ritter and Sue (2007a, 2007b, 2007d). Consultation with stakeholders, including wheelchair users, was an important part of this process. The resulting survey included a combination of Likert scale items and ranked responses, as shown in Appendix A. This version of the survey was administered nation-wide, following ethical approval from the University of Otago Human Ethics Committee (Health) (reference H14/07).

Participants

Potential participants living in New Zealand were invited to participate if they were 18 years or older, used a wheelchair for mobility at least 50 percent of the time, and were residing in the community. They self-identified as meeting these inclusion criteria, rather than being screened. Wheelchair users living in residential care facilities were excluded because they do not face the same emergency-related issues as wheelchair users living in the community.

Recruitment

Recruitment used the snowball sampling method, which relies on potential participants being referred by their peers. According to Ritter and Sue (2007c), this method can be effective when there is no clear sampling frame. This was the case for the current research because New Zealand based wheelchair users come from geographically, socially and diagnostically diverse backgrounds and usually have more than one type of funding support. This means there is no comprehensive, pan-disability, list of people who use a wheelchair for mobility.

We approached organisations who advocate for, or provide services to, people with disabilities - especially those with mobility impairments. An email was sent to 79 individuals within various disability organisations throughout New Zealand. The email contained a brief overview of the research aims, a pre-prepared advertisement for use in publications or notifications, a copy of the written information sheet, and the link to a webpage with further information. The 79 individuals were asked to advise their organisation's members about the survey using any means, including but not limited to: email, newsletters, publications and Facebook.

Snowball sampling was achieved by asking the same individuals to forward the email and associated content to any other individuals or organisations that they felt was appropriate. Health service providers throughout New Zealand were also approached and asked to refer suitable participants to the study, in a similar way to the service and advocacy organisations. Health service providers' contacts included home care/support agencies and allied health professionals working with wheelchair users. The latter were contacted via district health boards' allied health leaders forums and the special interest groups of professional bodies for physiotherapy and occupational therapy. A further 16 people or organisations were contacted as a result.

Data collection

Participants were able to complete the survey online, or as a paper-based survey. Paper-based surveys were directly provided by the researchers. Copies were also made available via health service providers before being posted back to the researchers. All paper-based survey data were manually entered as part of the online data.

Analysis

All data were then exported from the online survey website for analysis using Statistical Package for the Social Sciences (Version 22, 2013). Descriptive statistical analyses included the frequencies of particular survey responses. Risk ratios were calculated with 95 percent confidence intervals. Statistical significance was set at a concomitant level of p < 0.05.

Results

One hundred and one individuals completed the survey; 84 online and 17 paper-based. The largest number of participant responses were from the Waikato (n = 19), Auckland (n = 18), Canterbury (n = 14) and Wellington (n = 13) regions. No responses were received from the Gisborne or Hawke's Bay regions or from the West Coast of the South Island. All participants indicated they had some or all of the following: provision of food and water, an emergency plan, organisation of a support network, stockpile of consumables/medication/disability specific requirements. There were 28 participants (28%) who indicated that they were prepared for an emergency. Of those, five were Māori and this represented nearly 50 percent of Māori participants in the study compared to 27 percent (n = 21) of the NZ European participants.

A slightly higher number of males (n = 51) than females (n = 47) completed the survey while three participants did not specify gender. There was an even spread of ages represented, with the exception of the youngest category: 18-24 year olds (n = 4). Four of the six remaining age categories had between 16 and 19 participants while the 55-64 year old category had the highest number of participants (n = 25). New Zealand Europeans accounted for 77 percent (n = 77) of participant ethnicities with 11 percent of participants (n = 11) identifying as New Zealand Māori and the remaining 13 percent being made up of other (n = 10, 10%), Cook Island Maori (n = 1, 1%). These characteristics and other participant demographics are summarised in Table 1.

Seventy one percent of the participants (n = 71) reported using a wheelchair for all their mobility needs, the remaining twenty-five percent of participants (n = 25) indicated they used a wheelchair but that they could also walk to some degree. Two participants reported

Table 1.

Demographic Characteristics of Participants

Demograp	hic variable	Total <i>n</i> ¥ (%)	Prepared for	remergency
			Yes	No
Age category (years)	18-24	4 (4%)	1	3
	25-34	17 (17%)	6	11
	35-44	19 (19%)	5	14
	45-54	17 (17%)	0	17
	55-64	25 (25%)	9	16
	65 or older	16 (16%)	6	10
Gender	Male	51 (50%)	16	35
	Female	47 (47%)	11	36
Ethnicity				
(participants were able to identify as more than 1 ethnic group)	NZ European	78 (78%)	21	57
	NZ Māori	11 (11%)	5	6
	Other	10 (10%)	1	3
	Cook Island Māori	1 (1%)	0	1
	Samoan	1 (1%)	0	1
	Chinese	1 (1%)	0	1
Main reason for mobility impairment	Spinal Cord Injury	52 (52%)	12	39
	Other neurological condition	34 (34%)	12	22
	Multiple sclerosis	6 (6%)	1	5
	Medical or degenerative condition	3 (3%)	1	2
	Amputation	2 (2%)	0	2
	Stroke	1 (1%)	1	0
Duration of mobility impairment	5 years or less	14 (14%)	4	10
	6-10 years	13 (13%)	5	8
	11-15 years	13 (13%	1	12
	16-20 years	11 (11%)	1	10
	More than 20 years	46 (46%)	16	30

Y Totals may not add to N = 101 due to missing data (participant non-response).

that they did not use a wheelchair. Their responses were still included because these participants had relevant mobility impairments and had simply used other forms of mobility devices such as mobility scooters. Just over a quarter of participants in both full time and part time wheelchair user groups reported being prepared. This equated to 27 percent (n = 19) of full time wheelchair users and 25 percent (n = 6) of part time wheelchair users surveyed.

Five of the nine participants who lived alone with no carers reported being prepared, compared to a quarter of participants in any other living situation (n = 22). Conversely, 15 percent (n = 27) of participants living with family/whānau or a partner and not requiring any carers reported being prepared. This compared to 32%

(n = 71) of participants in any other living situation. Only one person out of 13 (8%) living in a rural location or township reported being prepared, compared with three (25%) living in towns and 16 (38%) living in cities respectively. These figures are summarised in Table 2.

Only 14 (14%) participants aged 35 to 54 years old reported being prepared. This was a significantly lower (p < .05) proportion than participants aged between 18 -34 years (33%), and participants over 55 years of age (36%) combined. Similarly, participants who had experienced a mobility impairment for 11 to 20 years were significantly less likely to be prepared when compared to participants with less than 10 years or over 20 years of mobility impairment. The only statistically significant demographic difference between these

Table 2.

Livina	Arrangements	and	Location	of	Participants

Demogra	• • •		•	ared for rgency	
			Yes	No	
Living	Live alone, no carers	9 (9%)	5	4	
situation	Live alone, carers	24 (24%)	7	17	
	Live with family/whanau/ partner, no carers	27 (27%)	4	23	
	Live with family/whanau/ partner, carers	26 (26%)	8	18	
	Live with others (eg: flatmates), no carers	4 (4%)	1	3	
	Live with others (eg: flatmates), carers	7 (7%)	2	5	
Rural or urban	Live in rural area/township (< 1,000 people)	13 (13%)	1	12	
location	Small town (1,000-10,000 people)	12 (12%)	3	9	
	Large town (10,000-50,000 people)	18 (18%)	7	11	
	City (Over 50,000 people)	55 (55%)	16	39	

Y Totals may not add to N = 101 due to missing data (participant non-response).

Table 3. Association between Age and Duration of Impairment with Preparedness

Demographic	Category	Risk Ratio	95% confidence interval range
Age	35-54 years	(ref)	XX
	18 – 34 years	2.4	0.8, 6.6
	Over 55 years	2.6*	1.0, 6.5
Duration	11 – 20 years	(ref)	XX
of mobility impairment	0 – 10 years	4.0	0.95, 16.7
impanment	More than 20 years	4.1*	1.0, 16.6

(ref)= reference group, * = statistically significant, p < 0.05

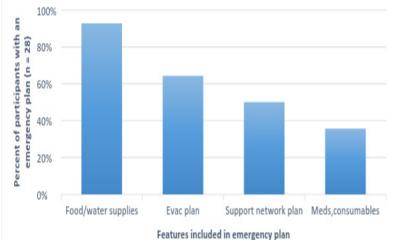


Figure 1. Items included in emergency preparations

groups was that participants with 11 to 20 years of mobility impairment were more likely to be full time wheelchair users (RR = 2.4, 95% CI (1.3, 4.5), p < 0.01). Further details are provided in Table 3.

There were no other statistically significant relationships identified between participant demographics, including gender, and emergency preparedness. However, subtle trends were observed relating to ethnicity, living situation, urban versus rural residence, and previous emergency exposure. These trends included higher rates of preparedness reported by Māori, participants living alone, and participants living in small towns or cities. Although it did not represent a statistically significant difference, thirty percent of participants who had been in a natural disaster were prepared compared to 26 percent of participants who had not.

Preparedness Responses

Provisioning food, water and other supplies was the most common preparedness action reported by participants. This aspect of preparedness was reported by 93 percent (n = 26) of the 28 participants who reported being prepared for an emergency. As shown in Figure 1, participants were less likely to have planned for more disability specific issues such as making an evacuation or support network plan, or stockpiling medications and other disability-related consumables. Note that the survey let participants select one or more features of their emergency plan, meaning that totals do not sum to 100 percent.

Seventy-three participants reported that they were not prepared for an emergency. Over half (n = 43, 58%) of these participants reported thinking about getting prepared without any physical preparedness. Twenty four percent (n = 17) of participants who were not prepared reported that they did not know what to plan for. Ten (14%) identified cost as a reason for not making emergency preparations and eight (11%) stated that they had not thought about it at all. Very few of the non-prepared participants (n = 4, 6%) stated that they had not taken any action because they did not think that preparedness was important.

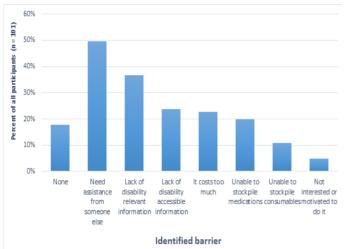


Figure 2. Emergency preparedness barriers identified by all participants

Among all 101 participants, need for assistance from others was the most common barrier to making physical preparations or planning. As shown in Figure 2, other barriers included: lack of disability relevant information, inaccessible information, cost, and being unable to stockpile medications or consumables. Only five participants reported that a lack of interest or motivation was a barrier to getting prepared for an emergency.

Discussion

The aim of this study was to investigate emergency preparedness among a population of disabled people living in New Zealand. Key results included that fewer than 30 percent of participants appeared to be prepared for an emergency. Participants' preparations tended to focus on having a general emergency survival kit, including food and/or water. However, fewer than 20 percent of all participants had provided for their own disability-specific requirements. Over 80 percent of participants who were not prepared had thought about preparedness but had not initiated any planning steps. The need for assistance from another person was identified as a barrier for over half of unprepared participants.

The current study sample was less prepared than the NZ population as a whole. Less than 30 percent of the participants in this study reported stockpiling emergency survival items. This is much less than a rate of 86 percent in the general NZ population (Colmar Brunton, 2014). While having emergency survival items is an important aspect of preparedness, being fully prepared also involves having and regularly updating emergency survival items, and having a plan that includes what to do

when at home or away (Colmar Brunton, 2014). Colmar Brunton (2014) found that only 15 percent of the general NZ population were likely to have both emergency survival items and a plan. This is similar to the current findings, where only 18 percent of participants reported having an emergency plan.

Only a small proportion of the current participants reported including disability specific items in their emergency preparations. Fourteen percent had a plan with their support network and only 10 percent had put aside disability-specific medications or consumables. These results are similar to findings in Phibbs et al. (2014) where 20 percent of survey respondents with a disability reported having adequate emergency supplies and 12 percent had reported having an emergency plan. At the time of writing, there was no way to readily compare the current results with preparedness among other subgroups of the general NZ population, for example, people living with chronic health problems.

Need for help from others was the most common barrier to personal preparedness among the current participants. This does not appear to be a barrier for the general NZ population (Colmar Brunton, 2014). People with mobility impairments are more likely to require external assistance to meet basic needs, to effect an evacuation, or to sustain care requirements in the aftermath of an emergency. This means they are less likely to be able to personally develop an effective plan. A number of other studies and reports (Bethel et al., 2011; Brereton, 2012; Castaneda, 2011; Fox, White, Rooney & Rowland, 2007; Hogan et al., 2011; Kailes & Enders, 2007; Markenson, Fuller & Redlender, 2007; Ministry of Civil Defence & Emergency Management, 2013; National Council on Disability, 2005, 2006) have identified this need for additional assistance, during and following an emergency.

Cost was a barrier for nearly a quarter of the current participants. This was a higher rate than among the general NZ population where 14% indicated that cost was a barrier (Colmar Brunton, 2014). This marked difference in cost-related barriers was also identified by Phibbs et al. (2014). Kohn et al. (2012) and Smith and Notaro (2009) have identified that low socioeconomic status is an additional risk factor to being less prepared, among populations with a disability.

The current results indicate that ethnicity may not be a barrier to emergency preparedness in New Zealand. Although the current results are based on a small sample, Māori participants reported the highest levels of preparedness. Kenney and Phibbs (2014) described Māori cultural practices which may facilitate disaster risk mitigation, recovery and community resilience. They noted that the cultural concepts of *whakapapa* (genealogy) and *whānau* (family) provide "a stable emergency management infrastructure for Māori" (Kenney & Phibbs, 2014, p. 759) and that the *marae* (Māori community) has, for centuries, been able to rapidly mobilise support at times of adversity. It is possible that Māori participants had an emergency plan that was based upon the collective preparedness of the *iwi* (tribe) or whānau , rather than the individual.

A lack of information that is relevant to, and accessible for, people with disabilities was identified as a barrier for current participants and participants in other national and international studies (Phibbs et al., 2014; Priestley & Hemingway, 2007; Spence, Lachlan, Burke, & Seeger, 2007; Sullivan & Häkkinen, 2010). It seems that emergency preparedness information needs to be tailored to suit a range of disability types. It has been recommended that the development and dissemination of information needs to involve disabled people working in partnership with emergency planning and response agencies (Connecticut Developmental Disabilities Network, 2005; Fox et al., 2007; National Council on Disability, 2005; Phibbs et al., 2012; Rowland, White, Fox & Rooney, 2007).

The current participants identified that a lack of disabilityspecific information was a barrier to emergency planning, rather than a lack of access to this information. New Zealand's disability specific emergency preparedness information nonetheless appears consistent with international guidelines. It is available in various languages and formats, including formats for people with vision impairments, and has been improved and updated following recent large seismic events in New Zealand (Federal Emergency Management Agency, 2015; Ministry of Civil Defence & Emergency Management, n.d.; National Organization on Disability, 2009). Concerns raised by our participants may therefore reflect a lack of awareness of the availability of relevant information, such as knowing where to find it. Concerns may also reflect an assumption that information will not be relevant to their specific needs. Further consultation may be required in any case, as outlined below.

Conclusion

Participants in this study were less prepared for emergencies than the general New Zealand population and this has the potential to increase their vulnerability during and following emergencies. Major barriers to emergency preparedness were:

- the need for assistance from another person to effect emergency preparations;
- awareness of and access to disability specific information;
- cost, and;
- an inability to stockpile disability related consumables, especially medications.

The main limitations of this study are the recruitment strategy and the small sample size. These sampling limitations have resulted in an inability to generalize results to the wider NZ disabled population. A snowball recruitment strategy was selected because the complex reasons leading to mobility impairment and reliance on a wheelchair for mobility meant the population sample was poorly defined in preexisting data. Snowball sampling is non-randomised. It may restrict the diversity of a sample because initial participants tend to refer people with similar characteristics to themselves (Ritter & Sue, 2007c). There is also a potential bias towards people with an interest in the topic. This bias may have led to an over-estimated level of preparedness among New Zealand wheelchair users.

The current research was also unable to control how, or to whom, information about the study was distributed. This meant we were unable to compare participant characteristics with characteristics of individuals who were eligible but who chose not to participate. This combined with the small and non-systematic sample to limit the generalizability of the current research study. Furthermore, while statistically significant associations between study variables were identified, the confidence intervals associated with some of these findings indicated uncertainty regarding where the true risks may actually lie.

The current research nonetheless highlights the need to focus on particular aspects of preparedness among people with disabilities. People with disabilities comprise nearly one quarter of all New Zealanders. This means there is a critical need for a comprehensive plan of further work and research to enable a truly inclusive emergency planning approach to future emergency events. In order to achieve this outcome, it is essential that emergency planners, responders and researchers actively partner with disabled people and their communities. This will help to ensure that planning and associated information meets the needs of, and improves outcomes for, disabled New Zealanders in emergency situations.

References

- Adams, V., Kaufman, S. R., van Hattum, T., & Moody, S. (2011). Aging disaster: mortality, vulnerability, and long-term recovery among Katrina survivors. *Medical Anthropoly, 30*, 247-270. doi: 10.1080/01459740.2011.560777
- Bethel, J. W., Foreman, A. N., & Burke, S. C. (2011). Disaster Preparedness among medically vulnerable populations. *American Journal of Preventive Medicine, 40*, 139-143. doi.org/10.1016/j.amepre.2010.10.020
- Brereton, R. (2012). Disability-inclusive emergency preparedness and response: learning from the Canterbury earthquakes: Key themes from a symposium held in Christchurch on 28 and 29 May 2012. Retrieved from www. odi.govt.nz/resources/guides-and-toolkits/emergencypreparedness-and-responsiveness/symposium-may-2012/ record-of-emergency-preparedness-symposiumseptember-2012.doc_
- Brunkard, J., Namulanda, G., & Ratard, R. (2008). Hurricane Katrina Deaths, Louisiana, 2005 Disaster Medicine and Public Health Preparedness, 2, 215-223. doi: 10.1097/ DMP.0b013e31818aaf55
- Castaneda, M. A. (2011). *Including people with disabilities in disaster preparedness: A delphi study.* (Doctoral Dissertation, Pepperdine University, Malibu). Retrieved from <u>http://pepperdine.contentdm.oclc.org/cdm/ref/</u> <u>collection/p15093coll2/id/211</u>
- Chou, Y. J., Huang, N., Lee, C. H., Tsai, S. L., Chen, L. S., & Chang, H. J. (2004). Who is at risk of death in an earthquake? *American Journal of Epidemiology, 160*, 688-695. doi: 10.1093/aje/kwh270
- Colmar Brunton (2014). *Ministry of Civil Defence and Emergency Management: Campaign monitoring research*. Retrieved from <u>www.civildefence.govt.nz/assets/Uploads/</u> <u>publications/grgt-survey-results-2014.pdf</u>.
- Connecticut Developmental Disabilities Network (2005). A guide for including people with disabilities in disaster preparedness planning. Retrieved from www.uconnucedd. org/pdfs/resources/a_guide_for_disaster_planning.pdf
- Doocy, S., Daniels, A., Packer, C., Dick, A., & Kirsch, T. D. (2013). The human impact of earthquakes: a historical review of events 1980-2009 and systematic literature review. *PLoS Currents*, *5*. doi: 10.1371/currents.dis.67bd 14fe457f1db0b5433a8ee20fb833
- Dunn, J., Nicholls, J., Cassidy, B., & Sinnott, K. A. (n.d.). Systems to Advise of Vulnerable Persons in Emergencies (SAVE): Wheelchair Users: Scoping Project Report. (Unpublished report)
- Federal Emergency Management Agency (2015). Prepare for emergencies now: Information for people with disabilities. Retrieved from <u>https://www.fema.gov/media-librarydata/1440775166124-c0fadbb53eb55116746e811f258e</u> fb10/FEMA-ReadySpNeeds_web_v3.pdf

- Fox, M. H., White, G. W., Rooney, C., & Rowland, J. L. (2007). Disaster preparedness and response for persons with mobility impairments: Results from the University of Kansas Nobody Left Behind Study. *Journal of Disability Policy Studies*, 17, 196-205. doi: 10.1177/10442073070170040201
- Fujii, K. (2012). The Great East Japan Earthquake and disabled persons: Background to their high mortality rate. Retrieved from <u>www.dinf.ne.jp/doc/english/twg/</u> escap_121031/fujii.html
- Gershon, R. R., Kraus, L. E., Raveis, V. H., Sherman, M. F., & Kailes, J. I. (2013). Emergency preparedness in a sample of persons with disabilities. *American Journal of Disaster Medicine*, 8, 35-47. doi: 10.5055/ajdm.2013.0109
- Hogan, T. P., Holmes, S. A., Rapacki, L. M., Evans, C. T., Lindblom, L., Hoenig, H., . . . Weaver, F. M. (2011). Disaster preparedness and response practices among providers from the Veterans Health Administration and veterans with spinal cord injuries and/or disorders. *Journal of Spinal Cord Medicine*, *34*(4), 353-361. doi: 10.1179/2045772311Y.0000000011
- IBM Corporation (2013). IBM SPSS Statistics for Windows (Version 22.0). Retrieved from <u>www-03.ibm.com/software/</u> products/en/spss-statistics
- Kailes, J. I., & Enders, A. (2007). Moving beyond "special needs". *Journal of Disability Policy Studies, 17*, 230-237. doi: 10.1177/10442073070170040601
- Kenney, C., & Phibbs, S. R. (2014). Shakes, rattles and roll outs: The untold story of Māori engagement with community recovery, social resilience and urban sustainability in Christchurch, New Zealand. *Procedia Economics and Finance, 18*, 754-762. doi: 10.1016/S2212-5671(14)00999-X
- Kohn, S., Lipkowitz Eaton, J., Feroz, S., Bainbridge, A. A., Hoolachan, J., & Barnett, D. J. (2012). Personal disaster preparedness: An integrative review of the literature. *Disaster Medicine and Public Health Preparedness*, 6, 217-231. doi: 10.1001/dmp.2012.47
- Levac, J., Toal-Sullivan, D., & O'Sullivan, T. L. (2012). Household emergency preparedness: A literature review. *Journal of Community Health, 37*, 725-733. doi: 10.1007/ s10900-011-9488-x
- Markenson, D., Fuller, E., & Redlender, I. (2007). *Emergency* preparedness: Addressing the needs of persons with disabilities: A national consensus conference: Executive summary and final report. Retrieved from <u>www2.ed.gov/</u> rschstat/.../guide-emergency-management-pwd.pdf
- Markwell, P., & Ratard, R. (2008). *Deaths directly caused by Hurricane Katrina*. Retrieved from <u>http://new.dhh.</u> louisiana.gov/assets/oph/Center-PHCH/Center-CH/stepi/ specialstudies/KatrinaDeath1.pdf
- McClure, L. A., Boninger, M. L., Oyster, M. L., Roach, M. J., Nagy, J., & Nemunaitis, G. (2011). Emergency evacuation readiness of full-time wheelchair users with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 92, 491-498. doi: 10.1016/j.apmr.2010.08.030
- Ministry of Civil Defence & Emergency Management (2010). Working from the same page: Consistent messages for CDEM. Retrieved from www.civildefence.govt.nz/cdemsector/consistent-messages-for-cdem/
- Ministry of Civil Defence & Emergency Management (2013). Including people with disabilities: Information for the CDEM sector. Retrieved from www.civildefence.govt.nz/

assets/Uploads/publications/is-13-13-including-peoplewith-disabilities.pdf

- Ministry of Civil Defence & Emergency Management (n.d.). People with disabilities or special requirements. *Get ready get thru.* Retrieved from <u>http://getthru.govt.nz/how-to-getready/people-with-disabilities/</u>
- National Council on Disability (2005). *Saving lives: Including people with disabilities in emergency planning*. Retrieved from <u>http://www.ncd.gov/publications/2005/04152005</u>
- National Council on Disability (2006). The impact of Hurricanes Katrina and Rita on people with disabilities: A look back and remaining challenges. Retrieved from <u>www.ncd.gov/</u> publications/2006/Aug072006
- National Organization on Disability (2005). *Functional needs of people with disabilities: A guide for emergency managers, planners and responders*. Retrieved from <u>http://nod.org/assets/downloads/Guide-Emergency-Planners.html#toc</u>
- National Organization on Disability (2009). *Disaster readiness tips for people with disabilities: Prepare yourself.* Retrieved from <u>http://nod.org/assets/downloads/Readiness-Tips-Disabilities.pdf</u>
- Office for Disability Issues (2013). *Disability and formal supports in New Zealand in 2006: Results from the New Zealand Disability Survey*. Retrieved from <u>www.stats.govt.nz</u>
- Officials' Committee for Domestic and External Security Coordination (2007). *National Hazardscape Report*. Retrieved from www.civildefence.govt.nz/assets/Uploads/ publications/national-hazardscape-report-sept-2007complete.pdf
- Phibbs, S. R., Good, G., Severinsen, C., Woodbury, E., & Williamson, K. (2014). What about Us? Reported experiences of disabled people related to the Christchurch earthquakes. *Procedia Economics and Finance, 18*, 190-197. doi: 10.1016/S2212-5671(14)00930-7
- Phibbs, S. R., Good, G., Severinsen, C., Woodbury, E., & Williamson, K. (2015). Emergency preparedness and perceptions of vulnerability among disabled people following the Christchurch earthquakes: Applying lessons learnt to the Hyogo Framework for Action. Australasian Journal of Disaster and Trauma Studies, 19, 37-46. URL: http://trauma.massey.ac.nz/issues/2015-IRDR/ AJDTS_19-IRDR_Phibbs.pdf
- Phibbs, S. R., Woodbury, E., Williamson, K., & Good, G. (2012). Issues experienced by disabled people following the 2010-2011 Canterbury earthquake series: evidence based analysis to inform future planning and best practice guidelines for better emergency preparedness. *GNS Science Report, 40*, 1-53. URL: www.whariki.ac.nz/ massey/fms/Colleges/College%20of%20Humanities%20 and%20Social%20Sciences/Psychology/Disasters/pubs/ GNS/2012/Phibbs_et_al_SR%202012-040.pdf
- Priestley, M., & Hemingway, L. (2007). Disability and disaster recovery. *Journal of Social Work in Disability & Rehabilitation*, 5, 23-42. doi: 10.1300/J198v05n03_02
- Ramirez, M., & Peek-Asa, C. (2005). Epidemiology of traumatic injuries from earthquakes. *Epidemiology Review*, 27, 47-55. doi: 10.1093/epirev/mxi005
- Riscoe, P., Schlegelmilch, J., & Paturas, J. (2013). Evacuation and sheltering of people with medical dependencies – Knowledge gaps and barriers to national preparedness. *Homeland Security Affairs, 9,* article 2. <u>www.hsaj.org/</u> <u>articles/234</u>

- Ritter, L. A., & Sue, V. M. (2007a). Introduction to using online surveys. *New Directions for Evaluation, 2007*, 5-14. doi: 10.1002/ev.230
- Ritter, L. A., & Sue, V. M. (2007b). Questions for online surveys. *New Directions for Evaluation, 2007*, 29-36. doi: 10.1002/ev.233
- Ritter, L. A., & Sue, V. M. (2007c). Selecting a sample. New Directions for Evaluation, 2007, 23-28. doi: 10.1002/ev.232
- Ritter, L. A., & Sue, V. M. (2007d). The survey questionnaire. New Directions for Evaluation, 2007, 37-45. doi: 10.1002/ ev.234
- Rowland, J. L., White, G. W., Fox, M. H., & 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*, 216-222. doi: 10.1177/10442073070170040401
- Smith, D. L., & Notaro, S. J. (2009). Personal emergency preparedness for people with disabilities from the 2006-2007 Behavioural Risk Factor Surveillance System. *Disability and Health Journal*, 2, 86-94. doi: 10.1016/j. dhjo.2009.01.001
- Smith, D. L., & Notaro, S. J. (2015). Is emergency preparedness a 'disaster' for people with disabilities in the US? Results from the 2006–2012 Behavioral Risk Factor Surveillance System (BRFSS). *Disability and Society, 30*, 401-418. doi: 10.1080/09687599.2015.1021413
- Spence, P. R., Lachlan, K., Burke, J. M., & Seeger, M. W. (2007). Media use and information needs of the disabled during a natural disaster. *Journal of Health Care for the Poor and Underserved*, 18, 394-404. doi: 10.1353/ hpu.2007.0047
- Statistics New Zealand. (2014a). 2013 New Zealand Disability Survey. Retrieved from www.stats.govt.nz/browse_for_ stats/health/disabilities.aspx
- Statistics New Zealand. (2014b). *Disability Survey 2013: All tables*. Retrieved from <u>www.stats.govt.nz/browse_for_stats/health/disabilities.aspx</u>
- Statistics New Zealand. (2014c). Social and economic outcomes for disabled people: Findings from the 2013 Disability Survey. Wellington, New Zealand: Statistics New Zealand.
- Sullivan, H. T., & Häkkinen, M. T. (2010). Preparedness and warning systems for populations with special needs: Ensuring everyone gets the message (and knows what to do). *Geotechnical and Geological Engineering*, *29*, 225-236. doi: 10.1007/s10706-010-9363-z
- United Nations. (n.d.). Disability, natural disasters and emergency situations. *United Nations Enable*. Retrieved from <u>www.un.org/development/desa/disabilities/issues/</u> disability-inclusive-disaster-risk-reduction-and-emergencysituations.html
- White, G. W., Fox, M. H., Rooney, C., & Cahill, A. (2007). Assessing the impact of Hurricane Katrina on persons with disabilities. Retrieved from <u>http://rtcil.org/products/</u> <u>NIDRR_FinalKatrinaReport.pdf</u>
- Wolf-Fordham, S., Curtin, C., Maslin, M., Bandini, L., & Hamad, C. D. (2015). Emergency preparedness of families of children with developmental disabilities: What public health and safety emergency planners need to know. *Journal* of Emergency Management, 13, 7-18. doi: 10.5055/ jem.2015.0213

Appendix A: Complete Survey Text

_	oll survey: Wheelchair users' readiness
About the s	urvey.
Thanks for show	ing interest in this survey.
what the survey haven't seen eit	this far, you have probably already read the information sheet or watched the video that explains is about, what your participation would involve and what you need to know to make a decision. If y her of these, you can still do so now by going to the website at the address below: ood.org.nz/projects
To continue to t	he survey click on the "next" button below.
*1. I have r	ead the information sheet or watched the information video and agree to
take part in t	
C Yes	
C No	
_	ever been in a natural disaster (eg: earthquake, flood, severe weather as caused damage to any buildings or infrastructure (eg: power, phone,
sewage)?	as caused damage to any buildings of infrastructure (eg. power, profie,
C Yes	
C No	
3. Do you cu	rrently have an emergency response plan?
C Yes	
C No	

eady to Roll survey: Wheelchair users' readiness	
. Yes, I have an emergency response plan which includes:	
elect one or more options from the list below	
Put aside provisions of food, water and other supplies	
Have an evacuation plan	
Have a plan with a support network who will check on each other in an emergency	
Made arrangements for medications, consumables and carers (if needed)	
Other (please specify)	
. No, I don't have an emergency response plan because:	
elect one or more options from the list below	
I've thought about it but not got around to it	
I've thought about it but it's not important to me	
I've not thought about it	
I don't know what to plan for or how to go about it	
I can't afford to do it	
Other (please specify)	

WY

14

Sel	ect one or more options from the list below
	None
	I need assistance from someone else to help with planning or making physical preparations
	Lack of information that is relevant to people with disabilities
	Lack of information that is accessible to people with disabilities
	Unable to stockpile consumables
	Unable to stockpile medications
	Financial. It costs too much to do it
	I am not interested or motivated to do it
Othe	er (please specify)
	n an emergency situation, who would you expect to check on you or come to bein
you	
	No one
	No one Family / whanau
	No one Family / whanau Friends
	No one Family / whanau Friends Neighbours
	No one Family / whanau Friends Neighbours Civil defence
	III? No one Family / whanau Friends Neighbours Civil defence Police
	No one Family / whanau Friends Neighbours Civil defence
	Image: Participant of the second of the s
	Image: Participant of the service
	No one Family / whanau Friends Neighbours Civil defence Police Ambulance Fire Service ACC GP
	In ore Family / whanau Friends Neighbours Civil defence Police Ambulance Fire Service ACC GP Carer agency or staff
	No one Family / whanau Friends Neighbours Civil defence Police Ambulance Fire Service ACC GP
	In ore Family / whanau Friends Neighbours Civil defence Police Ambulance Fire Service ACC GP Carer agency or staff

	adiness
Have you made formal plans with any of the indiv	iduals or organisations above to
neck on you in the event of an emergency?	
Yes	
No	
omments:	
Do you think that a voluntary Disabled Persons E	mergency Response Register, to
ssist with emergency planning, preparation and re	esponse is a good idea?
Yes	
No	
Unsure	
omments:	
	×.
	7
). If one was developed, would you participate in a	a voluntary Disabled Persons
). If one was developed, would you participate in a mergency Response Register?	a voluntary Disabled Persons
	a voluntary Disabled Persons
mergency Response Register?	a voluntary Disabled Persons
mergency Response Register?	a voluntary Disabled Persons
Yes	a voluntary Disabled Persons
Yes No Only if my concerns were adequately addressed	a voluntary Disabled Persons
Yes No Only If my concerns were adequately addressed Don't know	a voluntary Disabled Persons
Yes No Only If my concerns were adequately addressed Don't know	a voluntary Disabled Persons
Yes No Only If my concerns were adequately addressed Don't know	a voluntary Disabled Persons
Yes No Only If my concerns were adequately addressed Don't know	a voluntary Disabled Persons
Yes No Only If my concerns were adequately addressed Don't know	a voluntary Disabled Persons
Yes No Only If my concerns were adequately addressed Don't know	a voluntary Disabled Persons
Yes No Only If my concerns were adequately addressed Don't know	a voluntary Disabled Persons
Yes No Only If my concerns were adequately addressed Don't know	a voluntary Disabled Persons
Yes No Only If my concerns were adequately addressed Don't know	a voluntary Disabled Persons
Yes No Only If my concerns were adequately addressed Don't know	a voluntary Disabled Persons

APTVN

	Which option below best describes your living situation?
-	Live alone, no carers required
	Live alone, carers required
	Live with family/whanau, spouse/partner, no other carers required
	Live with family/whanau, spouse/partner, carers required
0	
	Live with others (flatmates / boarder etc.), carers required
th	er (please specify)
0.	. What type of building is the home you live in?
9	
0	2 or more storey, stand-alone house
0	Unit or apartment - single storey
0	Unit or apartment – part of 2 or more storey building
0	Single storey house or unit within a complex (eg: retirement village, marae)
th	er (please spedity)
-	
1.	. What do you use for mobility most often?
	What do you use for mobility most often?
0	
0	Fulltime manual wheelchair Manual wheelchair, can walk a bit (with or without aids)
0	Fulltime manual wheelchair Manual wheelchair, can walk a bit (with or without aids)
0	Fulltime manual wheelchair Manual wheelchair, can walk a bit (with or without aids) Fulltime power wheelchair
	Fulltime manual wheelchair Manual wheelchair, can walk a bit (with or without aids) Fulltime power wheelchair Power wheelchair, can walk a bit (with or without aids)
	Fulltime manual wheelchair Manual wheelchair, can walk a bit (with or without aids) Fulltime power wheelchair Power wheelchair, can walk a bit (with or without aids) Do not use a wheelchair but have limited mobility
	Fulltime manual wheelchair Manual wheelchair, can walk a bit (with or without aids) Fulltime power wheelchair Power wheelchair, can walk a bit (with or without aids) Do not use a wheelchair but have limited mobility
	Fulltime manual wheelchair Manual wheelchair, can walk a bit (with or without aids) Fulltime power wheelchair Power wheelchair, can walk a bit (with or without aids) Do not use a wheelchair but have limited mobility
	Fulltime manual wheelchair Manual wheelchair, can walk a bit (with or without aids) Fulltime power wheelchair Power wheelchair, can walk a bit (with or without aids) Do not use a wheelchair but have limited mobility
	Fulltime manual wheelchair Manual wheelchair, can walk a bit (with or without aids) Fulltime power wheelchair Power wheelchair, can walk a bit (with or without aids) Do not use a wheelchair but have limited mobility

	y: Wheelchair users' rea	adiness
2. What is the main rea	ason for your mobility impairr	nent?
C Stroke		
C Multiple Scierosis		
C Traumatic Brain Injury		
C Spinal Cord Injury		
Other neurological condition (eg	2: Parkinsons disease, Motor Neuron Disease, M	Muscular Dystrophy)
C Amputation		
Medical or degenerative condit	ion (eg: arthritis, cancer, COPD)	
Other (please specify)		
3. How long have you	had a mobility impairment?	
5 years OR LESS		
C 6 - 10 years		
C 11 - 15 years		
C 16 - 20 years		
MORE THAN 20 years		
24. What region of New Select your region from the drop down menus	Zealand do you live in? North Island / Te-Ika-a-Maul	South Island / Te Walpounamu
25. Do you live in a rura	il or urban area?	
C Live in a rural area or township		
C Small town (1,000 - 10,000 per	opie)	
C Large town (10,000 - 50,000 p	eople)	
C City (over 50,000 people)		

Wirm

Ready to Roll survey: Wheelchair users' readiness
26. What age bracket do you belong to?
C 18 – 24 years
C 25 - 34 years
C 35 - 44 years
C 45 - 54 years
C 55 - 64 years
C 65 years or older
27. What gender are you?
O Male
C Female
28. Which ethnic group do you belong to?
Mark the space or spaces which apply to you.
New Zealand European
Maori
Samoan
Cook Island Maori
Tongan
Niuean
Chinese
Indian
Other such as DUTCH, JAPANESE, TOKELAUAN. Please state:
That's the end!
Many thanks for taking the time to complete this questionnaire.
If you wish to make any enquiries about this survey, or receive a copy of the grouped results, please contact Jason Nicholls by email: nicja964@student.otago.ac.nz
Alternatively, if you have any concerns about ethical issues related to this survey please contact Gary Witte (Human Ethics Committee Administrator, phone +64 3 479 8256 or email gary.witte@otago.ac.nz.)