

Covid 19's impact on disabled people in NZ: – knowing and responding

Earthquake Disability Leadership Group (Jan 2020)

Purpose

The purpose of this paper is to distil the main themes arising from the experiences reported by disabled people and their whanau in Canterbury, from meetings, reports, surveys and the media. Importantly, it identifies possible policy responses to both redress the current situation, and to embed into future planning for emergency situations. The paper documents peoples' experiences, and the main ways the emergency response 'system' (egs services, funding etc.) did or did not respond. We believe that these two perspectives understood together will provide a foundation for future improvements.

Structure of the paper

First, the paper provides background and rationale for the approach taken. Then general issues are explained, followed by a table examining the major categories of system, policy and process responses, and recommended future actions from a disability perspective. Finally, Conclusions reflect on next steps.

Background

The Earthquake Disability Leadership Groups (EDLG) was formed in response to the 2010/11 earthquakes, as an active network of disabled leaders and allies to identify and support resolution of particular issues for the Canterbury disability community, ensuring disabled people's voices were included in the recovery and rebuild. The EDLG is re-focusing on general disability issues, continuing its kaupapa in a Covid-19 context.

Health/Disability in All Policies

This report takes the perspective that health and wellbeing outcomes are the responsibility of many sectors, often called 'social determinants of health'. We know that disabled people are overrepresented in poor outcomes, with a range of social factors interacting, egs education, employment, health, income. There is a fundamental equity issue and a responsibility for decision-makers to take action to address this. We suggest reference to the recent publication by Statistics NZ <https://www.stats.govt.nz/reports/measuring-inequality-for-disabled-new-zealanders-2018>. Also, a recent report on NZ's progress in addressing the human rights of disabled people provides important contextual information <https://www.ombudsman.parliament.nz/resources/making-disability-rights-real-2014-2019-0>

General themes

Variability. While experiences of disabled people were different there are also similarities. The impacts were magnified beyond the usual experiences of disability. Communication remained one of the important safeguards for everyone. Disabled people experienced varying levels of marginalisation. The different experiences of disabled people are not surprising in that we are all individuals. For instance, some disabled professionals who were able to work from home, found lockdown very different from people who rely on the community for their social participation. So, there will not be consensus on some points. What matters is to identify those areas where disabled people had more disadvantages, and act on those that can be remediated.

Information. Some impairments result in the need for particular communication approaches – termed accessibly formatted information. We all need information in an emergency; and a lack of relevant information to us can colour the whole experience. The so-called digital divide is also a key factor.

Personal care. Disabled people and the people who provided support had to trust each other and / or figure out ways to keep safe that were outside the direction of the Ministry of Health. Disabled people who rely on caregivers are particularly challenged in an emergency situation. Covid-19 impacted many support and care arrangements. The general trend towards an increased range of care in the home has resulted in many medically oriented activities considered personal care – for example until recently, suprapubic catheter changes were done in sterile hospital facilities. Disabled people who use respirators can live at home with appropriate care. Decision-makers need to understand both the key role of carers coming into people’s home, and the jobs they do, in order to make safe provision for PPE.

System complexity and need for linkages. Disabled people’s lives are significantly affected by a complex set of funding and service arrangements. The Covid-19 situation has revealed areas where roles and responsibilities were not clear, and better linkages were needed. We note that there was an attempt by the Ministry of Health to allow more flexibility in support arrangements and are pleased that some flexibility has continued. This is evidence of disabled people using resources both wisely. Higher trust relationships clearly work.

Strengths-based. Disabled people live with daily challenges in a world that is not always designed for their situation. Policy makers must recognise that strengths, based on skills, knowledge and experience, can provide a foundation for policy responses. Involving disabled people in the development of solutions, ‘nothing about us without us’, is just good, sensible policy.

Issues	Impact of system, policy and process responses	Future actions from a disability perspective
Physical Health	<p>Some (but not all) disabled people fall into a ‘vulnerable’ category due to the nature of their impairments; however, all disabled were deemed vulnerable and told to stay home.</p> <p>Many health services closed or restricted access; and these changed over time.</p> <p>Example – no visitors and limited support people access for hospitals and age-related care facilities.</p> <p>Difficult to get accurate information on availability of various health services.</p> <p>Difficult to access primary care.</p> <p>Some health services offered phone and video consultations.</p> <p>Many disabled people have existing strengths and strategies to cope.</p>	<p>Acknowledge diversity in disabled population and sometimes labels are not helpful.</p> <p>Up to date information requirements for disabled people met by single points of contact that holds local information.</p> <p>Acknowledge that one rule does not fit all – CDHB relaxed visitor policy for disabled patients but did not communicate clearly, internally or externally.</p> <p>Provide PPE (see below) with broad eligibility guidelines.</p> <p>Continue to offer phone and video consultations as options.</p> <p>Health services should plan with disabled people, for future emergencies, based on strengths approach.</p>

Issues	Impact of system, policy and process responses	Future actions from a disability perspective
Mental Health	<p>Stress and worry re risks, impact, social distancing, uncertainty about the future. The environment and communications triggered existing mental health issues or bring on new ones</p> <p>For some people, change is difficult. Needed to plan 'bubble' arrangements amidst much uncertainty re what supports will be available.</p> <p>Interpersonal challenges of living in a 'bubble' during lockdown.</p> <p>Concern that others are not social distancing</p> <p>Lack of usual support people and services. Some support organisations reached out to members and checked in.</p> <p>Many disabled people have existing strategies to cope and supportive families/friends.</p>	<p>Put a focus on mental health promotion – All Right?, encouragement to seek help and wider dissemination of where to get help 1737, websites, online resources etc.</p> <p>Develop/adapt mental wellbeing messaging that considers disability.</p> <p>Establish one stop shop for information.</p> <p>Provide PPE so people feel (and are) safe (see below).</p> <p>Support development of resilience capacity for disabled people (e.g., Trisha Ventom 5 ways to wellbeing workshops)</p>
Culture	<p>All the systematic responses were individualised when some people needed to be supported in their context i.e., whanau. Manaaki 20 led by Whanau Ora in Canterbury provided wrap around support that was based on need and trust. This in turn built resilience and reciprocity amongst whanau.</p>	<p>The principles of Whanau Ora benefit all communities including the disability community. Learnings need to be shared and seen as relevant</p>
Disability support services	<p>Some support people were not available, at a time when support and information were essential. Anecdotes of care workers 'not turning up'.</p> <p>Changes to support services e.g., day programmes, respite.</p> <p>In lockdown, day services were not available.</p> <p>Lack of respite services – impacting children, people with learning disability, dementia – added stressor.</p> <p>Day programme closure had variable impacts. Some challenges from changes to routine, home relationships, etc; alternatively, for some, decreased stress from needing to be in groups.</p>	<p>Develop arrangements for future emergencies for those who receive support in their home.</p> <p>Fund support agencies for additional costs to deliver services in emergencies.</p> <p>Increase the number of disabled people on individualised support arrangements, with flexibility and control by disabled people.</p> <p>Find a way for NASC to continue during emergencies, if only by phone.</p>
Food	<p>Difficulty accessing nutritious, affordable food.</p> <p>Supermarkets adopted one-person only policies.</p>	<p>Supermarkets should set up registration for disabled people to get priority in home deliveries.</p>

Issues	Impact of system, policy and process responses	Future actions from a disability perspective
	<p>There were technology problems for those not digitally connected e.g., to order home delivery, people who only use cash.</p> <p>Capacity barriers developed for home deliveries which were quickly oversubscribed.</p> <p>Some home based support providers were not permitted to shop for clients.</p> <p>Some were and spent a lot of time on shopping.</p>	<p>Plan with each home support services client, how they will access food in an emergency.</p> <p>Encourage, where possible, disabled people to plan ahead food supplies access and already on hand.</p> <p>Clarify shopping rules for carers, making sure some arrangement is in place for everyone.</p>
Medication and medical supplies	<p>Worries that medication and supplies that come from overseas may not be available.</p> <p>Pharmacists report 'they are the last to know' about shortages.</p> <p>Many community pharmacies offered free deliveries, but 'big box' pharmacies charged.</p>	<p>Review pharmacy and other supplier contracts re requirements for free home deliveries in emergencies.</p> <p>Review supply chains and stockpile some items that are found to be high risk egs continence supplies.</p> <p>Have better communication with pharmacists about problem areas, so they can advise customers.</p>
Communication of Information	<p>NZSL interpreters in daily updates helped remove information barriers.</p> <p>Lack of information on where to get advice on disability topics.</p> <p>Lack of information specific to their personal situation</p> <p>Over time, there was improved use of accessible information formats and disability focused information.</p> <p>Health serviced increased use of accessible information formats in addition to NZSL.</p> <p>Video conferencing and phone consultations a good option– GPs, Outpatients enhances access to health services, reduces social isolation</p> <p>1737 mental health line overloaded.</p> <p>Note: particular issues for Deaf people are outlined below</p>	<p>Plan for coordination and communication that includes disabled people from the earliest indications.</p> <p>Implement recommendation on Access to information and communication -enable disabled people to communicate more effectively with government agencies by increasing the number of accessible formats available so that disabled people can express their views in New Zealand Sign Language, and use braille, Easy Read and audio formats to engage fully.</p> <p>https://www.ombudsman.parliament.nz/resources/making-disability-rights-real-2014-2019-0</p>
Digital divide	<p>Access to computers and smart phones is lower amongst disabled people.</p> <p>Necessary information resided on websites and communication required access via cell phones.</p> <p>Paying bills on line was not able to be done for those not already set up for this.</p>	<p>Adjust comms approach to address digital divide.</p> <p>Use accessible format comms.</p> <p>Plan for libraries or other organisations to provide internet access even during lockdown situations, and let people know where and how to do this.</p>

Issues	Impact of system, policy and process responses	Future actions from a disability perspective
	Libraries, which are a key source of internet access, were closed during lockdown.	
Deaf people	National information sources e.g., Healthline, 1737 overloaded, not a good option for Deaf. Contact tracing for deaf people by phone meant inability to cont. Use of NZSL interpreters from beginning of 'stand ups' was positive.	There should be a full review of the Covid-19 experience from the perspective of Deaf people. New systems, policies and processes should be put in place as a result.
Personal Protective Equipment (PPE)	PPE not available as needed for home care. Guidance on correct use was unclear, changing. Concern decision-makers had a lack of understanding of what happens in home care e.g., Advice given to carers it is OK not to use PPE in home - just keep 2 metres away.	There should be a full review of how PPE was handled, with views of disabled people and families strongly represented. New systems, policies and processes should be put in place as a result.
Transport	Transport is critical for access to the community To protect bus drivers, bus services required patrons enter from the back entrance, but the accessible entrance was the front entrance. Total Mobility taxis were free for a period, but availability of drivers meant few were on the road during lockdown.	Review transport issues for future emergency situations.
Financial	Disabled people, with lower average incomes, incurred hardship with extra living costs. Job losses – self and others' – especially affected Maori and Pacific people. Differences for disabled people depending on whether they have ACC funding, MoH funding, DHB funding, or none of these. Changing rules and new arrangements not communicated well. MoH DSS relaxed purchasing guidelines, e.g., carer support \$ to purchase supplies – This was well received with comments that it meant needs were met; improved choice and control.	Increase disability support allowances in emergencies. Funders come to agreement on arrangements in emergencies with aim of 1) clarity 2) closing gaps and 3) reduced differences between funder categories.

Conclusions

The early experiences of Covid-19 in Canterbury represent an enlightening case study for how the challenges we all faced, were magnified for disabled people. And how strengths came to the fore, and short and longer range solutions were identified. The job now is to enact those solutions.

We believe that the UN Convention on the Rights of Persons with Disabilities provides an excellent framework for future action. The New Zealand Government, as a signatory state party, is responsible for ensuring the wide-ranging Convention articles are fully actioned. The Independent Monitoring Mechanism recently published a report on the pandemic response to date:

<https://www.ombudsman.parliament.nz/resources/making-disability-rights-real-pandemic>