

How Canterbury disabled people experienced the Covid-19 lockdown in Aotearoa New Zealand

Data collected during a workshop facilitated at an Earthquake Disability Leadership Group (EDLG) Network Meeting on Friday 07 August 2020

Strengths: What worked well for disabled people and their families?

Access to family and support networks

- Moved in with family to keep safe and in control
- Having personal support networks e.g. family
- Bonded together by spending more time together
- *'If not had my parents ... to take me in ... three months of bliss with Mum taking care of me ... helped me through'*

Spring cleaning

- *Chance to sort out household items*
- *Photos sorted into photo albums and gave photos to family*
- Decluttered e.g. bagged up clothes
- People do their gardens

Technology

- *'Rebirth of technology – got to know things that I didn't know before'*
- Zoom: fun and rewarding experience, contact a lot more people, keep up communications with people
- More self-reliance as can Zoom now

- Ability to Zoom – *kids got in touch with me; saw more of my grandchildren; sign with sister in (Australia); easier than expected e.g. talked my 85-year-old Mum how to use it*
- More people involved in Zoom e.g. use sign language
- Technology easier
- Had good internet connection

Activities

- Going out for walks
- More activities (e.g. jigsaw puzzles, going for walks, going out in the van, participate in people first Zoom meetings)
- Liked staying at home – crafts, baking, going for walks

Agency checking in

- *'Held the region together by ringing around people to make sure everyone was connected'*
- *'Emerge and ABC connected and their support was amazing. Connected before the lockdown ... mindfulness, encouraging ... every day a text message'*
- More checking on people from organisations ... texts and phone calls. *'Texting was my life saver.'*

Social capital increased

- Networked with people
- *Sit on front porch and people stop to talk*
- Increased sense of community in neighbourhoods – see people across the street and talk
- Pre-Covid people too busy, but during Covid people emailed and called

Enhanced physical and mental health wellbeing

- Improvements in physical health of medically fragile person as locked away from others
- Coughs and colds – managed to stay out of hospital as not exposed to others bugs
- Self-care: more time to think about what was important, eating well
- City had clean air, bike around safely

- *More time to myself to listen to music without the structures of pre-covid experiences*
- *Enjoyed being by myself and not pressure by others*
- *Flexibility and casual approach - roll out of bed into Zoom meetings*
- Children from special needs schools did well

Social cohesion

- Stay at home, stay safe message – positive reinforcement to stay at home
- People fell into line, followed the rules – made me feel secure
- *Community feel like after the EQs*

Government's Response

- Government did well with Covid messages via social media and TV
- Government Covid website did a good job
- 1pm briefings every day by Jacinda and Ashley ... *kept us informed and kept the fear down ... reassuring*
- *Up-to-date information good to have even if numbers climbing as you knew that people were working behind the scenes*
- Good to have sign language interpreters
- Disabled and elderly heard – trying hard to meet their needs
- Government implemented the wage subsidy system quickly
- Welfare checks were important

Innovation

- *Used stock of paper with my contact details on them so people could contact trace before contact tracing was officially introduced*

Working/studying

- *Get up at the same time and finish at the same time ... not distracted by people ... delivering to people in need*
- *UC put in place classes online before the lockdown Isolated myself so available to support people*
- *Being an essential service gave me a reason to get up in the morning*
- *More productive as no office disruptions*
- *Essential workers got recognised for their efforts e.g. supermarkets increased workers' wages*

Lockdown and Level 2 rules

- *We know about social distancing*
- *For someone with anxiety and claustrophobia, social distancing at supermarkets was the best of experiences ... having physical space and not huge numbers of people in the supermarket was great*
- *At level 2 went to a café ... usually hard to get a chair round a table ... extra physical space to place your chair and not have it kicked by others*
- *Enjoyed the lockdown – number of people in a bubble and if someone broke the bubble, they were not allowed back in.*

Getting resources

- *Student volunteers' army had systems in place so they could react quickly ... used this model in other areas ... wanted to help by delivering groceries, getting equipment to people*
- *Online buying especially groceries*

The Challenges: What was more difficult during lockdown?

Lack of accessible bathrooms for some people in their homes. Usually they shower at community facilities such as QEII after exercise, but during lockdown they had no access to community bathrooms. Some arranged portable showers/bathrooms through support networks/services. Without these portable bathrooms they would have been unable to shower/bathe.

Lack of understanding from local and national government and people working in support services about the realities for disabled people and their whānau. Suggestions communicated for organising support workers were impractical, e.g. keeping 2-metres away from people when working. *“How can we shower/dress/eat 2 metres apart?” “The people making the decisions did not understand our situations.”*

Anxiety and fear during lockdown and after it was lifted. Perceived risk in the community made for a fearful experience when venturing out to get groceries, etc. *“It felt alien.”*

Funerals being restricted and keeping distance at funerals was hard. No access to people dying. Could not go through tangihanga process as a whānau. This increased trauma. *“Our cultural values were just brushed aside”.*

Not enough food at home. Hard to access food. Hard to afford food.

Triggered mental health issues during lockdown after experiencing institutions such as residential care, prisons, mental health facilities, etc. Lockdown was a similar experience and brought up past trauma.

QR codes impractical at Level 2 or 3 for many disabled people. No solution for people with low vision. Many codes didn't work. People didn't necessarily have phones to use the technology. Also hard for people to write down their details on the contact tracing sheets as a secondary option.

PPE access difficult for disabled people and support staff. Didn't show up until end of lockdown. Lack of clarity about what PPE was needed, what to use, and how to access it. Particularly hard to get masks. DHB allocations created an issue. Fear and uncertainty created as a result.

Communications from government unclear / impractical. Told what to do by government/ministries but not 'how' to do it. Different interpretations led to different practices across the sector.

Lack of anxiety/mental health support specifically for disabled people. *"Wanted contact about mental health/wellbeing."*

Hospital visiting policies made difficult situations for people in the spinal unit even harder. People with recent life-changing spinal injuries were unable to see whānau through their recovery. No visitors were allowed.

Peer support not seen as 'essential' for people with disabilities struggling in many ways, e.g. peer support people could not operate in the spinal unit to support patients while family could not visit.

Isolation. No whānau support. Longer lockdown made this harder. Being stuck inside. Not being able to go out was hard on wellbeing. Lack of connection with other people.

Carer issues. Maintaining bubbles with carers coming in and out was very hard. Had staffing issues. Hard to get support staff over lockdown, particularly quality support staff. This is an ongoing issue.

Online shopping was hard because everyone was using it. Couldn't get groceries and other products in time, which meant we had to go out to the supermarket, even with a medical issue.

Hard to get out and do shopping. Lack of support to do it.

Lack of usual routines made life hard. *"Couldn't go to day base. No activities or social stuff."*

Politics/Media created fear. Dramatic news stories. Unclear who to listen to about what.

Too many meetings at work. Technology meant a lot of meetings. No time to do actual work. A lot to cope with on top of lockdown. 'Zoom Fatigue'.

Contact tracing hard to document with carers and whānau coming in and out of home to support us. Unclear what to document and how.

Too many agencies and not for profits communicating. Too much information. Overwhelming. Lack of clarity about who to go to for what. *“What services are out there? We didn’t know.”*

Having to repeat information to different agencies/services. They should be able to balance privacy with the practicality of sharing info where needed to save us time and hassle.

Had to stay with whānau instead of in usual home because of support staff issues/maintaining bubble. Families who had moved family members out of residential care/ rest homes then struggled to support their whānau member and to access support to help them. Support workers were often not assisting parents/ whānau over Covid to maintain bubbles.

Technology and internet access were issues, either due to affordability or getting it set up with Spark/Vodafone, etc. Long wait times. Expensive. Hard to set up at home without practical support. Knowing which apps, devices and software to have was also difficult without support, which meant people couldn’t access what they needed to do on their devices. *“We didn’t know what questions to ask and of who to. Getting hold of reliable affordable WiFi was hard.”*

Poverty and low incomes an issue for many disabled people and whānau.

Prioritising needs and how to cope was hard, e.g. when to do online shopping in advance so you didn’t run out of food with delayed delivery times. *“Nothing worked the usual way.”*

Waiting for online shopping. Delays in delivery and in orders due to postal system and huge number of orders. Essential items delayed.

No legislation around shopping access for disabled people/elderly/those in need in a pandemic to ensure we can access everything in a timely fashion, e.g. groceries, medical items getting delivered quickly.

Accessing continence supplies was hard and delayed, particularly while staying with parents/whānau outside of usual DHB area. Had to get back up supplies from personal stock sent from Christchurch to

Wellington and arrange the whole process as Wellington providers could not get catheters sent in time. Unacceptable to be unable to access basic essentials.

Housing situations not ideal/safe. Drinking within house. Domestic abuse from parents/whānau. Stuck in flatting situations with people who I had not chosen to live with (shared flat with other disabled people). Lockdown compounded issues in the home that were already there.

Family carers not safe. Family had to care in lockdown with no support workers available within bubble. Abuse suffered at hands of whānau. *“Why are family carers not vetted before being allowed to support us alone?”*

Ideas/Opportunities for the future: How could things be improved in the future (or now)?

Recognise the full range of issues for disabled people – learn from experience so far

Recognise number of people affected by disability

Individuals, whanau/families, carers, carer's bubbles etc.

Profile of disability types and particular issues for each (in general, of course everyone is an individual)

Better representation by disabled people at all levels of decision-making

Nothing about us without us

Establish a single point of contact for particular issues

Who to go to for PPE?

Stop having to argue the case, exhausting, confusing

Develop guidelines in accessible formats – how to use PPE

Improved supply chain for PPE – active supply chain management

Barely works for non-disabled, terrible for disabled

Recipients of home care/personal care services/Rest homes

Designated stocks for each group pre-allocated – home and hospitals should not compete for limited supplies

Integrate stock rotation

Improved access to food and household supplies

Prioritise online and delivery services for disabled people

Address those with food allergies vs foodbanks

Make hygiene packs available on request

Recognise some people only use cash to make payments.

Improved access to medications and medical supplies

Build in safeguards to supply chains.

Offer an 'emergency supply' for items that come from overseas, so people can stockpile these.

All pharmacies should deliver, or arrange for delivery.

PPE should be free, at least to those on low incomes

Flexibility to use people-centred approaches. (Example of leaving region for 5-week lockdown requires discharge from Nurse Maude after 4 weeks and being assessed and picked up by new provider, and then reversed when return home to Christchurch).

Improved home support services/personal care

When support system breaks down, whanau/families only option. Some went without care entirely (e.g. people in flats who get 5-10 hours/week carers)

Plan and publicise communication routes to clients and their families/whanau

Have to prevent carers 'not showing up'

Better contingency planning for when carers are not available (funders need to recognise cost)

Reduce to an absolute minimum having carers work in different places and multiple bubbles

Improved access to daily 'check in' support

Recognise value and offer 'how is it going?' 'what do you need' services to all on request, provide support, linkages, referrals.

Develop a hierarchy of linkages/referrals so system provides appropriate level of services.

Set up system so people sign up for this ahead of time, in format they choose e.g. phone, text, email, relay.

Consider whether there is a role for Healthline in this?

Recognise complexity of 'digital divide'

Develop ways to support people to 1) access 2) get set up, learn how to use devices 3) keep using devices when problems emerge (help line/tech support that understands disability/non-techies – not everyone can 'download the app')

Encourage Paywave by waiving costs for businesses.

Better emergency preparedness (systems)

Explanation of EOCs (Emergency Operations Centres), Civil Defence roles, responsibilities, how to contact

Establish relationships among organisations before emergency (Waimakariri given as good example this is in place)

Identify and publicise points of contact for disabled people – more than DSS in Wellington, need local contacts, consider DIAS, give DIAS contracts that commence upon emergency and enable additional resources to be sought. Clarify Citizens Advice role.

Set up network/phone tree of NGOs and even voluntary orgs/trusts/church groups

Examine the 'bubble' concept in relation to disabled people – how can bubbles be bigger but still safe?

Better emergency preparedness (disabled people)

Make a plan for your own physical and mental health in lockdown – tools for managing eg daily routine, healthy sleep patterns, keeping positive, giving and receiving support e.g. by phone, email, text.

Make a shopping list of your regular supermarket items in case someone else has to do your shopping.