

# Clinical guidance for responding to patients with an intellectual (learning) disability during COVID-19 in Aotearoa New Zealand

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These guidelines are underpinned by the principles of:

- Te Tiriti O Waitangi
- New Zealand Disability Strategy (Whakanui Oranga)
- Whāia Te Ao Mārama: The Māori Disability Action Plan
- Faiva Ora 2016–2021: National Pasifika Disability Plan
- The United Nations Convention on the Rights of Persons with a Disability (Te Kawenata o te Rūnaka Whakakotahi i kā Iwi o te Ao mō kā Tika o kā Tākata Hauā).

These guidelines are being provided to ensure equity for people with an intellectual disability.

## Why are we providing this guidance?

People with an intellectual (learning) disability<sup>1</sup> are at a heightened risk of having a poor outcome from infection with COVID-19 in comparison to non-disabled people. International studies indicate that cardiovascular disease and pneumonia – either from infection or aspiration, are leading causes of death for people with an intellectual disability. They are also more likely to have chronic conditions such as diabetes and respiratory illnesses such as asthma.

People with an intellectual disability commonly report having poor experiences with health services generally. This is often due to the manner in which they are responded to and the lack of time taken to ensure that they are adequately assessed and treated. Socio-economic factors, such as rates of poverty amongst people with intellectual or learning disabilities also increase the impact of poor health outcomes due to limited access to regular health visits.

On average this population group die 20 years earlier than their New Zealand contemporaries without disabilities despite having conditions amenable to appropriate healthcare. For Māori and Pasifika people living with intellectual disabilities these health issues are compounded, resulting in even poorer outcomes.

These guidelines are being provided to ensure that people with an intellectual disability have:

- equal rights to COVID-19 testing and treatment
- equitable access to COVID-19 resources, supplies and care

<sup>1</sup> The term intellectual disability is used to ensure consistency with New Zealand Law and policy acknowledging that is it not the preferred term of of Ngā Tāngata Tuatahi-People First New Zealand, a learning disability Disabled Person's Organisation.

- the accommodations necessary to ensure that they can access COVID-19 testing and treatment.

It is important to remember that people will have a range of abilities and needs that are likely to be able to be met simply through establishing what they require and making reasonable accommodations.

As a signatory to the UNCRPD, health services within Aotearoa New Zealand are expected to ensure that all disabled people and tāngata whaikaha (disabled Māori) can access the health care provided to the rest of the population with additional support to enable this to happen. This means that health professionals have a responsibility to ensure they are meeting the needs of this community adequately.

The UNCRPD defines reasonable accommodations as necessary and appropriate modification and adjustments to ensure persons with disabilities are able to enjoy or exercise their human rights and freedoms. Most accommodations required by tāngata whaikaha and other disabled New Zealanders in health contexts relate to communication, or the physical environment.

In Aotearoa New Zealand reasonable accommodation can also be taken to include responding to tāngata whaikaha in a way that upholds the mana (authority) of the person you are assessing or treating, and to ensure that manaaki (support) is provided for the person receiving health and disability services, and their whānau.

## Background information

Approximately 2% of the overall population of Aotearoa New Zealand have an intellectual disability. Māori have slightly higher rates of learning disability than non-Māori.

The majority of people with an intellectual disability in Aotearoa New Zealand are living within their local community. Some live independently, while others are supported by their whānau or by a disability support service.

People who are living independently may not have additional support to meet their health needs within their whānau or disability support services. It is critical that you deliver any additional health supports and information they need in a supportive and accessible way.

The majority of those living independently have a low income which means that they might delay accessing health care due to cost. They may have a poor experience of accessing health services in the past. In addition, they might not recognise the importance of their symptoms. This may lead them to present for COVID-19 testing or treatment with more advanced illness.

## What you can do to support people with an intellectual disability

In the first instance, you can support people by:

- taking more time
- using clear and plain language communication
- planning appointments in a way that meets the person's needs
- including whānau or support workers with the person's permission
- providing timely information and follow-up with the person and their whānau or supporters
- providing referrals where needed.

## Key practice points:

1. Most people with an intellectual disability will be able to consent to their COVID-19 test and treatment (see guidelines for informed consent from the MCNZ).

In order to provide informed consent, some people might need the health professional to adapt the way that they would usually communicate with other patients. This could include:

- a. finding a way to make the information the person requires meaningful to them, using simple sentences and avoiding medical terms if they are unnecessary
  - b. utilising strategies that the person would normally use for communicating, including gesture dictionaries, social scripts, technology and picture boards
  - c. checking their understanding by asking the person direct questions, using words or phrases that they know in reference to their body/health. Consistency in responding can be further checked by reframing questions. This avoids assuming that the person is agreeing to treatment, rather than responding as they think you want them to.
2. Some people may not know what testing for COVID-19 involves, and may not be familiar with the practices being promoted as necessary to reduce the spread of the virus. For these individuals, careful explanation will be required, along with the use of visual diagrams and in some cases repeated to ensure the person understands.
  3. Use plain language to provide all the details that they might need to get to the testing site, and what will happen when they get there. Ask if they will be bringing a support person. Provide clear information about each step of the COVID-19 test or treatment before you begin, including showing them the equipment that will be used.
  4. Listen to the person, their family, whānau or support workers. Most people can speak for themselves and want you to speak to them directly. However, with their permission, whānau and support workers might be able to provide additional information about other conditions, their medication and their usual responses when well.
  5. Ask if the person has a health passport or similar document and use these to guide care. A health passport provides essential information about how the person communicates and how to support them when they use health services. While all DHBs across Aotearoa New Zealand are encouraged to use health passports, they are still in the process of being fully adopted so do not expect every patient with a learning disability to have one.
  6. People with an intellectual disability experience the same illnesses as everyone else. It is important that their COVID-19 symptoms are recognised as attributable to the illness and not to their disability.
  7. The way in which individuals present or respond to their symptoms might include a range of behaviours, including crying, laughing, repetitive questioning, trying to hurt themselves or others and becoming withdrawn.

In addition to being responses to symptoms, these presentations might be a response to the unfamiliar environment, including the physical place and the people and procedures that they don't know.

Ask the person what would help them to feel more comfortable. Things that can help include:

- providing a quiet space away from other people
- adjusting lighting
- minimising the number of clinicians that work with the person.

8. When a person with an intellectual disability presents for testing for COVID-19 and does not have whānau or a support person with them make sure that the supporter is also provided with the information they need to fulfil their support role throughout testing and treatment.  
People should have their chosen support person available when being tested or treated for COVID-19. This may require the support person to also wear PPE.
9. Whether or not they are being supported by a disability service or living independently, each individual must be provided with the same health service support that other members of the population receive within their community when they are unwell but do not require hospital care.
10. Some people will be anxious about the testing procedure for COVID-19 as well as whether or not they have COVID-19. Minimising the waiting time for a test can help to reduce some of the anxiety. However, if a person presents with obvious anxiety it is important to check with them as their anxiety could also be about something else.
11. Explain the timeline and procedure for reporting of test results and, where possible, ensure that the result of their test is reported to them as soon as possible to reduce unnecessary anxiety. Also ensure that they have their chosen whānau member or support person available if they need treatment for COVID-19 to assist with understanding the care that will be put in place around them. Make sure the information provided after the test is in an accessible format such as large font plain English or Easy Read so that the person can revisit it as many times as they need to.
12. In addition to family, whānau and support workers, some DHBs have specialist intellectual disability services available who could assist the frontline health professionals with advice and clinical support. If these teams are not available in the region, Disability Support Services, preferably one already supporting the person, could be approached for general guidance. When seeking advice remember to abide by the Code of Health and Disability Services Consumers' Rights by protecting the privacy of the person.

## Useful resources

The updated 2016 version of the New Zealand Disability Strategy (2001) (Whakanui Oranga) is available at: <https://www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/pdf-nz-disability-strategy-2016.pdf>

The United Nations Convention on the Rights of Persons with Disability can be accessed at: <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/>

Whāia Te Ao Marama 2018 to 2022: The Māori Disability Action Plan is available at: <https://www.health.govt.nz/system/files/documents/publications/whaia-te-ao-marama-2018-to-2022.pdf>

For more on safeguarding against disability discrimination and promoting equity for disabled people during COVID-19 go to: <https://www.ucucedd.org/wp-content/uploads/2020/04/Center-for-Dignity-in-Health-Care-fact-sheet-on-rights-for-people-with-disabilities.pdf>

Communication strategies <https://www.ideas.org.au/uploads/resources/404/working-with-people-with-intellectual-disabilities-in-health-care.pdf> (scroll to the last page for a quick guide).

For information on health passports see: <https://www.hdc.org.nz/disability/health-passport/>

For guidance from MCNZ on informed consent processes see:

<https://www.mcnz.org.nz/assets/standards/79e1482703/Statement-on-informed-consent.pdf>

Easy Read documents at <https://covid19.govt.nz/communities/accessible-information/easy-read/>

Looking after yourself when you are sick

Looking after how you are feeling while staying at home

What is Coronavirus and COVID-19?

People First New Zealand Ngā Tāngata Tuatahi have provided their helpline number for people with learning disability who need some help 0800 20 60 70

## References used to evidence this guideline

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Annual mortality review for people with learning disability in England:

[http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR\\_Annual\\_Report\\_2018%20published%20May%202019.pdf](http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_Annual_Report_2018%20published%20May%202019.pdf)

New Zealand Disability Survey (2013).

[http://archive.stats.govt.nz/browse\\_for\\_stats/health/disabilities/DisabilitySurvey\\_HOTP2013.aspx](http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx)

The New Zealand Health Survey

<https://www.health.govt.nz/publication/annual-update-key-results-2018-19-new-zealand-health-survey>

Down Syndrome clinical guidelines prepared by the Ministry of Health in 2001

<https://www.health.govt.nz/system/files/documents/publications/downssyndrome.pdf>

# Acknowledgements

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