

# COVID-19 vaccine must be prioritised for people with intellectual disability

People with intellectual disability experience exclusion, discrimination and neglect every day in New Zealand, including during our COVID 19 lockdown, and we don't want to this continue when the COVID-19 vaccine is rolled out nationwide.

Many countries, states and territories have prioritised disabled people in their vaccination rollout and New Zealand needs to do the same.

People with intellectual disability have been identified by the World Health Organisation as a vulnerable population during public health emergency situations and this means they should be prioritised in the New Zealand vaccination strategy.

### People with intellectual disability have a higher risk of contracting COVID-19.

- They often cannot socially distance because they have personal carers that they rely on to do everyday things.
- · They often live in group settings.
- They often do not have appropriate information provided to them about COVID-19 and how to protect themselves.
- They are sometimes unable to use face masks, isolate, or wash their hands frequently due to their disability (e.g. may find the feeling of wearing a mask unbearable, could have memory issues).
- They are more likely to have underlying medical conditions that make them more vulnerable to the virus.

## Intellectually disabled people with COVID are more likely to die from COVID-19 than other populations.<sup>1, 2, 3</sup>

- They are more likely to have a pre-existing disease that increases the risk of COVID-19, such as a respiratory disease.
- For people with Down syndrome there is a four-fold increased risk for COVID-19–related hospitalization and a 10-fold increased risk for COVID-19–related death.
- They may not have access to adequate health provisions due to lack of money, transportation.
- They are likely to be de-prioritised by healthcare workers based on discriminatory medical judgments about quality of life.

 $<sup>^{1}\</sup>text{https://www.fairhealth.org/press-release/new-fair-health-study-uncovers-relationship-between-covid-19-comorbidities-and-mortality}$ 

<sup>&</sup>lt;sup>2</sup>https://www.upstate.edu/news/articles/2020/2020-06-02-iddresearch.php

<sup>&</sup>lt;sup>3</sup>https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities/covid-19-deaths-of-people-identified-as-having-learning-disabilities-summary

https://www.acpjournals.org/doi/10.7326/M20-4986

#### Vaccination of intellectually disabled people must be prioritised.

- It should not be based on the age of the intellectually disabled person (e.g. only for intellectually disabled people over 55)
- Appropriate information about the vaccine and COVID-19 must be provided to
  every intellectually disabled person before they choose to be vaccinated or not.
  The information should be in an easy to understand video format or easy read.
  Autonomy and legal capacity of all persons with disabilities including persons
  with intellectual disabilities, persons with psychosocial disabilities and people with
  autism must not be undermined with justifications such as public good or best
  interest of the person
- · It needs to be extended to their support workers.
- Vaccination sites need to be physically accessible and have appropriate in-person assistance available for people who need it.

#### New Zealand also needs:

- Specific outreach needs to be conducted to intellectually disabled people, so they know about the vaccines and the risk of COVID-19.
- Assurance that Disabled People's Organisations and other disability groups are meaningfully included in the policy making and planning for the vaccine rollout.

#### Support needs to be provided for informed consent.

- No-one has the legal authority to force or coerce any citizen to accept the COVID-19 vaccination. The fact that a person with disability may not have enough understanding regarding a decision should signal a requirement for the provision of supports in order to ensure that the decision-making capacity of the individual is enhanced to the greatest degree possible.
- Utilising such supports may enable the individual to communicate their choice or provide persons who know the individual best, with enough knowledge to identify their will and preference.

#### Intellectually disabled people can refuse to be vaccinated.

- The vaccination is not mandatory, and decisions made by intellectually disabled people to refuse the vaccinations must be respected.
- It is important to point out that no other person such as a family member, next of kin, friend or carer and no organisation, such as IHC, can give or refuse consent on behalf of an adult person who lacks capacity to consent unless they have specific legal authority to do so.
- Healthcare workers and support people should explore why the person does not want to be vaccinated. If the individual has needle phobia or anxiety, it may be appropriate to work with them and use role plays or reassurance to see if this can be overcome. The person must also have information provided, in a format that they understand, about what it means to not have the vaccination.