



What if a substitute decision maker says no to COVID-19 vaccination?

Information for disability support providers supporting adults with intellectual disability

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All Australians aged 5 years and older are encouraged to get vaccinated against COVID-19. Vaccination against COVID-19 is particularly important for many people with intellectual disability who have other health conditions or find it hard to understand and comply with social distancing and other COVID protection measures.

Consent and the COVID-19 vaccination

COVID-19 vaccination is voluntary. A medical professional can only provide COVID-19 vaccination to a patient where consent is provided.

Generally, for people aged 16 and over who can understand about vaccination, a decision to get vaccinated (or not) is theirs to make. People with intellectual disability should be provided with the information and support they need to make a decision about COVID-19 vaccination themselves. This process is called supported decision-making.

Further resources on consent and supported decision-making can be found at the end of this document.

Substitute decision makers

State and territory laws outline who can make medical decisions on behalf of an adult who does not have capacity to provide consent. These people are substitute decision makers.

Substitute decision makers may:

- be people who are automatically granted power to make medical decisions on someone's behalf (e.g. a close family member), or
- be someone who is formally appointed as a guardian (i.e. by a civil and administrative tribunal).

Substitute decision makers should act in accordance with certain principles in state and territory laws. Generally, they are required to promote the person's wellbeing and be respectful of the person's known wishes and preferences and, in the case of medical decisions, the advice of their treating doctor.

What can disability support providers (providers) do if a substitute decision maker/family member withholds consent for vaccination?

If a substitute decision maker withholds consent on behalf of an adult with intellectual disability and there is no medical reason for that decision, there are some steps providers can take.

Speaking to substitute decision makers, providing information, and facilitating further conversations

Providers can speak to the substitute decision maker about why they have withheld consent for vaccination. Substitute decision makers may be withholding consent for various reasons, including:

- they may have had negative experiences with health professionals in relation to the person with intellectual disability and find it hard to trust medical advice
- they may have concerns about the safety of vaccination
- they may not understand why vaccination is important, or
- they may be unaware of their obligations as a substitute decision maker.

Providers can help by identifying the reason why someone is withholding consent for vaccination and providing information/resources that help to address those concerns (some resources are included at the end of this document).

Substitute decision makers may also benefit from conversations with:

- a trusted GP
- a disability advocate, or
- another substitute decision-maker. For example, a parent who has withheld consent for vaccination may be more comfortable discussing their concerns with another parent of a person with intellectual disability.

Providers can help by encouraging or facilitating these conversations.

Applications to a state or territory tribunal

It is important to try hard to work the situation through with the relevant substitute decision maker before an application to a state or territory tribunal is considered.

For adults with disability, an application seeking consent for vaccination may be made to the relevant state or territory guardianship tribunal where a substitute decision maker has withheld consent for COVID-19 vaccination and that decision:

- contradicts the person's known values or wishes,
- goes against medical advice, or
- puts a person at risk of serious illness.

The tribunal would consider the person's situation and may make a decision about the person's vaccination or appoint a guardian to make that decision.

An application to a tribunal may be made by a provider, an advocate or a doctor. An application to a tribunal should be considered a last resort.

Two published decisions of the NSW Civil and Administrative Tribunal provided consent for the vaccination of people with disability, following refusal from a substitute decision maker (family member) are:

- [KQN \[2021\] NSWCATGD 22](#)
- [TKQ \[2021\] NSWCATGD 23](#)

Further Resources

Resources on COVID-19 vaccination and consent and preparing for vaccination

- The Department of Health has published [information for people with disability about COVID-19 vaccines](#). This includes information about COVID-19 vaccination in Easy Read.
- The Australian Commission on Safety and Quality in Healthcare provides information on [informed consent](#).
- The NDIS Quality and Safeguards Commission has published information for providers on checking consent, preparing for vaccination and restrictive practice. Further guidance on supporting conversations relating to COVID-19 is available in the COVID-19 information pack for providers. This is also available on the Commission's [website](#).

Resources on supported decision making:

- [Supported Decision Making is a Human Right – NSW Department of Communities and Justice](#). This four-minute video shows how informal support can build everyone's decision-making capacity.
- [La Trobe Support for Decision Making Practice Framework Learning Resource](#). This training presents the first evidence-based framework to guide the process of supporting people with cognitive disabilities to make decisions.
- [Supported Decision Making](#). ACT Disability Aged and Carer Advocacy Service (ADACAS) has a series of resources which raise some good questions for those supporting someone to make decisions.

Resources for substitute decision makers

- The [National Standards on Public Guardianship](#) are outlined in this Easy Read sheet from the Australian Guardianship and Administration Council.
- [Advanced Care Planning Australia](#) publish resources about [being a substitute decision-maker](#).

State and territory public guardian, trustee or advocate authorities

State	Organisation/resource
Australian Capital Territory	Public Trustee and Guardian - www.PTG.act.gov.au/guardianship
New South Wales	Public Guardian - www.tag.nsw.gov.au/public-guardian
Northern Territory	Office of the Public Guardian - www.publicguardian.nt.gov.au
Queensland	Office of the Public Guardian - www.publicguardian.qld.gov.au/ Making health care decisions for others - https://www.publicguardian.qld.gov.au/health-decisions/making-health-care-decisions-for-others
South Australia	Office of the Public Advocate - Guardianship Office of the Public Advocate (opa.sa.gov.au)
Tasmania	Public Trustee and Guardian - https://www.publicguardian.tas.gov.au/
Victoria	Office of the Public Advocate- www.publicadvocate.vic.gov.au/ and Guideline on the administration of the COVID-19 vaccine - Office of the Public Advocate
Western Australia	Office of the Public Advocate - https://www.wa.gov.au/organisation/departments/department-of-justice/office-of-the-public-advocate/making-treatment-decisions-opa-information

Further watching/reading

This webinar on [COVID-19 Hesitancy and Refusal](#) addresses issues about COVID-19 vaccine consent, hesitancy and refusal when supporting people with intellectual disability, and what to do if a substitute decision-maker won't engage in a discussion about vaccination.

The Council for Intellectual Disability has published [an article](#) on what to do if a family is concerned about the COVID-19 vaccination and does not give consent.