



Barriers to COVID-19 vaccination for people with an intellectual disability

Nov 2021



Inclusion Australia: Barriers to COVID-19 vaccination for people with an intellectual disability

1 November 2021

Acknowledgments

Inclusion Australia acknowledges the traditional owners of the land on which this publication was produced. We acknowledge the deep spiritual connection to this land of Aboriginal and Torres Strait Islander peoples. We extend our respects to community members and Elders past and present.

Inclusion Australia recognises the efforts of self-advocates who have courageously told their stories and worked tirelessly over the years for equality and human rights for all.

Inclusion Australia prepared this submission. To write this submission, we listened to the voices and concerns of people with intellectual disability and their families and advocates through our member organisations. We thank them for sharing their experience and expertise.

This paper

This paper was prepared in limited time by Inclusion Australia. It comprises of consolidated feedback from the Inclusion Australia member organisations collected for the Disability Vaccination Roundtable convened on 29 October 2021 by Senator the Hon Linda Reynolds CSC, Minister for Government Services and Minister for the National Disability Insurance Scheme

Contact

Inclusion Australia (NCID) Limited
ABN: 60 084 254 809

Catherine McAlpine
Chief Executive Officer
PO BOX 336
Nunawading, Victoria, 3131 Australia

P: 1300 312 343
M: 0419 530 524
E: catherine.mcalpine@inclusionaustralia.org.au
E: admin@inclusionaustralia.org.au
W: www.inclusionaustralia.org.au

About Inclusion Australia

Inclusion Australia is the national Disability Representative Organisation representing the rights and interests of Australians with intellectual disability and their families.

We have state members in New South Wales, Queensland, South Australia, Tasmania, Victoria, and Western Australia:

- Council for Intellectual Disability (CID)
- Parent to Parent (P2P)
- South Australian Council on Intellectual Disability (SACID)
- Speak Out Association of Tasmania (Speak Out)
- Victorian Advocacy League for Individuals with Disability (VALID), and
- Developmental Disability WA (DDWA)

Inclusion Australia was founded in 1954 and was previously known as the National Council on Intellectual Disability (NCID). Our mission is to work to make sure people with intellectual disability have the same opportunities as people without disability.

Inclusion Australia works in systemic advocacy, projects, information and communication activities that advance the rights and interests of people with intellectual disability.

We thank our members for their contributions to this paper:



People with disability have a right to good health care.

People with an intellectual disability need tailored support to access a COVID-19 vaccination

People with an intellectual disability are at higher risk from COVID-19

A study from Jefferson Health published on 5 March 2021 in the *New England Journal of Medicine (NEJM) Catalyst*, found that intellectual disability is second only to older age as a risk factor for dying from COVID-19. The study puts individuals with an intellectual disability at higher risk than the general population, for a variety of medical and institutional reasons.

Vaccination coverage is too low

Despite the higher risk COVID-19 poses for people with an intellectual disability, significant barriers to vaccination remain. Inclusion Australia understands that approximately 37% of Victorian NDIS participants with intellectual disability remain unvaccinated, and information from our members suggests the situation is similar or worse in other States & Territories.

There is an urgent need to gather information as to why people with an intellectual disability, especially people living in congregate living situations, are not vaccinated. In particular, the extent of parental and family consent hesitancy needs to be ascertained.

Recommendations related to information and data

Recommendation #01

Specific data on the vaccination rates for people with an intellectual disability by LGA be collected and reported.

Recommendation #02

Implement a concerted system to identify unvaccinated people with disability, especially people with an intellectual disability, as well as the reason why they are not vaccinated. This could include information gathering via:

- vaccination providers during the provision of in-reach second and third shots and boosters in group homes
- disability service providers, especially providers of SIL & SDA
- independent advocacy organisations (will need resources)
- membership organisations (will need resources, advice, and support on the process of information gathering)

Emerging barriers to vaccination access

Two major barriers to vaccine access have emerged:

1. Consent confusion
2. Lack of support for people with complex support needs

1. Consent confusion

What is consent confusion?

Consent confusion is when health professionals and/or disability service providers do not understand how to determine whether a family member (or other supporter) may provide consent for a person with an intellectual disability to be vaccinated.

IA members observe that disability service providers and health professionals are:

- not providing sufficient decision support to a person with an intellectual disability who is capable of making their own decision about whether to have a vaccination. In particular, people are not being specifically supported to speak directly with their GP.
- not raising legitimate concerns about the capacity of some individuals with an intellectual disability to make the decision to be vaccinated (often because of a fear of breaching the person's human rights)
- asking the wrong people to provide substitute consent, including family members who have no legal substitute decision-making standing
- not taking the appropriate steps to ensure that people who are authorised to be a substitute decision-maker have fulfilled their obligations under the relevant legislation
- unaware of other legal options of last resort, such as guardianship orders

The critical role of the GP

IA members observe that disability service providers and health professionals are not clear about the role of the treating GP in the determination of capacity and the choice of decision support. In particular, understanding that the role of the doctor:

- includes providing advice on the medical safety or risk for each individual person
- includes providing advice on which vaccine/s the person could or should receive
- could include a determination of the capacity of the person to make the decision
- **does not** include choosing who gives consent in the event the person is deemed not to have the capacity to make the decision – there are other rules about this

The responsibilities of supportive and substitute decision makers

No-one wants to be in conflict with supportive or substitute decision-makers, especially when they are family members. Nonetheless, all parties - disability and health providers, as well as families and other supportive and substitute decision makers - need to understand their obligations when it comes to vaccination decisions.

In particular, substitute decision-makers must fulfil their obligations under the relevant legislation. While the following advice is based on the Victorian legislation, Inclusion Australia understands the questions to be considered by substitute decision-makers are similar across jurisdictions.

1. What was the treating doctor's advice?
2. What would you reasonably believe the person would want?
3. What is in the best interests of their personal and social wellbeing?

In particular, substitute decision-makers must understand their own opinion for themselves is not part of the equation.

Health and disability providers need to be confident a substitute decision-maker has fulfilled their obligations before accepting a decision to accept or refuse a vaccination.

Last resort options

If a health or disability service provider is concerned that a supportive or substitute decision-maker has not fulfilled their obligations under the relevant legislation, applications to guardianship tribunals should be considered. These should generally be a last resort option (as it is in relation to a wide range of non-vaccination related issues) and be restricted to the vaccine decision itself.

Recommendations to reduce consent confusion

Recommendation #03

The NDIS Commission to issue a clear, authoritative statement to which independent advocates and disability service providers can refer. The statement must clearly outline the steps a provider must take to:

- ensure an NDIS participant has received appropriate decision support related to COVID-19 vaccination, including whether the participant has had an opportunity to consult with their treating doctor and access to an independent advocate
- determine if a person with an intellectual disability has the capacity (with support) to make a decision about consent or refusal for a COVID-19 vaccine, including who has the authority to make this determination
- confirm a person (including a close family member) claiming authority to provide substitute consent or refusal for a COVID-19 vaccine on behalf of an NDIS participant actually has this authority
- ensure a person who has authority to provide substitute consent or refusal for a COVID-19 vaccine fulfills their requirements under the relevant legislation
- arrange support for hesitant family substitute decision makers including from other parents of people with disability
- consider if a last-resort application to a guardianship tribunal is required

Recommendation #04

The Department of Health to issue a clear, authoritative statement for health professionals about what roles they may have in:

- determining individual capacity to make a decision about consent or refusal for a COVID-19 vaccine
- providing support for decision-making
- the provision of individualised advice on the medical safety or risk of vaccination relative to the risk of contracting COVID-19 for each person
- the provision of individualised advice on which vaccine/s the person could or should receive

The statement should also make clear the relevant rules about how substitute decision-makers are appointed and the limitations of the treating health professional's role in this appointment.

2. Lack of support for people with complex support needs

What are complex support needs in the context of vaccination?

Typically, people with an intellectual disability experience more interactions with the health system as well as more invasive procedures, which can lead to trauma. Some people with an intellectual disability also have other complex behaviour support needs that are triggered by one of the many barriers to access to vaccination. People with intellectual disability report some common issues include:

- fear of needles
- fear of doctors / health settings such as surgeries or hospitals
- trauma from previous restrictive practice in relation to injections
- fear of side effects from the vaccine
- isolation, with no formal or informal support to understand vaccine issue and/or access vaccine clinics
- an assumption they will receive a medical exemption from vaccination

Some people have not tried to access vaccination on the assumption they will be able to obtain a medical exemption. However, there is a low understanding that medical exemptions are only for people at risk of an adverse outcome from the vaccine itself. A complex medical history may not be a reason in and of itself.

Tailored responses for people with an intellectual disability work

Inclusion Australia acknowledges that recently significant recent outreach work has been undertaken by the NDIA and Department of Health and that resources have been strengthened. However, people with intellectual disability report they need in-person local support, not telephone support (e.g., from the Disability Gateway).

People with intellectual disability have reported feeling afraid about getting a vaccination, and felt better after:

- talking to their doctor, and
- talking with their peers

Victorian Disability Liaison Officers have been successful in supporting over 6,000 people with disability who needed individual support to get vaccinated.

Example 1

Janie*, a woman with an intellectual disability living in WA, is in her early sixties was unsure what vaccine to get. She lives alone and was worried about getting sick after the vaccine and being alone with no one to look after her. Janie has low literacy and finds paperwork hard to understand. She was not able to make a vaccination booking on her own.

Janie experiences needle phobia and was ‘really scared’ about having to have two needles. She also expressed uncertainty about where to go to get a vaccine or which bus to catch to get there.

The DDWA solution was one of the project team members took Janie to the vaccination centre on her day off and then drove her home. She also checked in with Janie as well as providing her own mobile number for Janie to call if she felt unwell anytime or was worried.

While this support is way outside the role of an ILC Project Manager, Janie needed someone she knew and could trust.

*Not her real name

Example 2

Sally*, a woman with an intellectual disability living in rural Tasmania, is in her fifties and received her first vaccine this week. Sally had been putting it off because she was worried about what people were saying about vaccinations and side effect. Also, she was concerned that the needle would hurt.

Sally received family support for this decision. Her family and friends had been checking in with her regularly about getting vaccinated and her nephew helped her to make the appointment and went with her. She said it was not too bad.

Sally said there was plenty of information around about the vaccine, it was mostly she was worried about what she would be like after the needle.

*Not her real name

Ongoing barriers to vaccination access

People with an intellectual disability and complex support needs and their families report ongoing barriers to vaccine access. Common issues include:

- people have not had the opportunity to talk through their fears with peers (this includes people with an intellectual disability and families)
- inadequate provision of in-reach to both people living in shared disability accommodation and people living with families
- people do not know how to access clinics equipped to offer personalised support including sensory sensitive environments
- people do not know how to access clinics equipped to offer 'low' sedation
- there are very few health services offering moderate to high sedation (there have been reports of services declining to offer this service. It is not clear whether this is a resource or risk issue).
- people do not know how to access clinics equipped to offer medium or high sedation
- sedation appointments are hard to get
- a lack of information about medical exemptions

Recommendations to improve vaccination access for people with complex support needs

Recommendation #05

Disability Liaison Officers (in health services) to be rolled out nation-wide

Recommendation #06

The Department of Health to develop fact sheets with State / Territory specific information for where people can access a low sedation appointment (e.g. list of GP clinics)

Recommendation #07

The Department of Health to develop system capacity for complex support, including in-reach and access to medium to high sedation appointments in every jurisdiction.

Recommendation #08

The Department of Health to develop fact sheets with State / Territory specific information for where people can access an in-reach vaccination or a medium to high sedation appointment.

Recommendation #09

The Department of Health to develop a tip sheet for strategies to address needle aversion

Recommendation #10

The Department of Health to develop a fact sheet that explains medication exemptions and supports people to access expert medical support and advice.

Recommendation #11

The Department of Health to enable an individualised, tailored approach to people with intellectual disability and their families to address vaccine hesitancy and concerns. This process needs to include the involvement of trusted GPs and the facilitation of separate peer to peer conversations for people with intellectual disability and their families.

Inclusion Australia suggests an appropriate approach would be a partnership with State & Territory governments to resource a mix of

- Disability Liaison Officers in health services
- Independent, individual advocacy, self-advocacy, and peer support organisations

Other concerns

Concerns of people about unvaccinated support workers

Inclusion Australia is hearing consistent comments about concerns people with an intellectual disability have about unvaccinated support workers – especially in jurisdictions that have not mandated that disability support workers be vaccinated.

While people often know their rights around asking their provider for vaccinated workers, filling shifts can be impacted and anyone who self manages faces gaps in their support.

In jurisdictions with no or low outbreaks, there are reports of requests about the vaccination status of support workers being ignored by service providers, or the response is uncertain.

Recommendation #12

The NDIS Commission targets communication about provider responsibilities to providers in areas on no / low COVID outbreaks

Promotion opportunities identified by people with an intellectual disability

People with an intellectual disability have made the following suggestions about how to promote vaccination positively:

- TV ads of famous people being vaccinated, including well-known people with disability
- Ads that show positive stories about life getting back to normal, such as people out and about, going to events and meeting up with friends ('this is what you'll miss out on')
- Showing TV ads during popular programs (especially in group homes) like
 - Home & Away
 - MasterChef
 - The Bachelor
 - Better Homes & Gardens

Recommendation #13

The Department of Health implement the communication suggestions from people with an intellectual disability