

Improving outcomes for people with disability in COVID-19

No one left behind

OZSAGE

Contributors to OzSAGE Working Party for People with Disability in COVID-19 (alphabetical order)

Professor Nancy Baxter (Member of OzSAGE Executive)

Ms Kate Cole

Professor Helen Dickinson

Associate Professor Nada Hamad

Professor Lisa Jackson Pulver (Member of OzSAGE Executive)

Professor Anne Kavanagh (Chair of Working Party)

Professor Lisa Maher

Professor Jackie Leach Scully

Professor Gwynnyth Llewellyn

Dr George Taleporos

Professor Julian Trollor

Dr Karina Powers (Member of OzSAGE Executive)

Background

People with disability are the largest minority group across the world. The 2018 ABS Survey of Disability, Ageing and Carers found that [18% of Australians](#) had a disability, representing 4.4 million Australians. Disability increases with age: 12% of Australians under 65 have a disability, compared to nearly half of Australians over 65. Nearly 6% of Australians have a severe or profound disability, which means they have significant limitations in core activities of communication, mobility, and/or self-care.

Human rights and people with people with disability

Australia is a signatory to the [United Nations Convention on the Rights of Persons with Disability](#) including the right to health (Article 25). Despite this, the Royal Commission into Violence, Abuse, Neglect and Exploitation against People with disability found that the Commonwealth Government has failed to respond to the [risks posed to people with disability during COVID-19](#) and has criticised the vaccine rollout among people with disability as '[seriously deficient](#)'.

The [United Nations Human Rights Commission](#) has expressed grave concerns about the impacts of the COVID-19 pandemic on people with disability. The Commission emphasise that while some people with disability have health conditions that make them more susceptible to COVID-19, pre-existing discrimination and disadvantage has meant that people with disability are one of the most excluded groups in terms of health, social and economic responses to the pandemic.

International evidence on risks to people with disability in the COVID-19 pandemic

Children and adults with disability are at increased risk both of contracting COVID-19 through infection with the virus SARS-CoV-2, and of experiencing serious disease or death.

These risks have been evident internationally, with studies in the United Kingdom and the United States reporting:

- Higher rates of [COVID-19 infection among people with intellectual disability](#), particularly those living in congregate settings (see [here](#), [here](#), and [here](#))
- Three to five times the risk of serious COVID-19 disease and hospitalisation among adults with intellectual disability (see [here](#) and [here](#)), with those with more severe intellectual disability and people with Downs Syndrome being at 13 and 36 times the risk [respectively](#).
- [Six to nine times](#) higher rates of hospitalisation for COVID-19 among children less than 16 years of age with intellectual disability compared to children without intellectual disability.
- Sixty percent of all deaths in England occurring among people with disability who were [two to three times](#) more likely than the general population to die from COVID-19, with greater disparities evident at younger ages

Post vaccination the risk of death from COVID-19 remains almost [13 times higher among people with Downs Syndrome and 2.6 times higher among people with neurological conditions](#), similar or higher than some populations classified as immunocompromised, such as people with recent cancer treatment and organ transplant recipients.

Why are people with disability 'at risk' during COVID-19?

There are number of reasons why people with disability are at risk of poor outcomes during COVID-19 related to individual (increased exposure to COVID-19, clinical vulnerability), structural (social and economic disadvantage), and systemic issues (poor access to health care, lack of coordination and regulation across the disability and health sectors).

Individual factors

Increased exposure to SARS-CoV-2

Infection with SARS-CoV-2 may be more common among people disability because:

- They require paid support to assist with daily activities and therapies. This brings them into contact with multiple staff who are likely to support other people with disability in a variety of settings, including private homes, disability residential settings, health care, care and protection including juvenile justice and prisons, and the community.
- People with disability live, learn and work in congregate settings which increases exposure. Outbreaks among people with disability have occurred in group homes and boarding houses. Some people including children and young people with disability are 'bussed' to schools or workplaces with other people with disability.
- They may have reduced awareness of, and ability to comply with, infection control measures such as mask wearing and physical distancing.

Clinical vulnerability

People with disability may also be clinically vulnerable, because of higher rates of conditions associated with poor COVID-19 outcomes, such as diabetes, high blood pressure, and compromised immune (e.g., associated with [Downs Syndrome](#)) and/or respiratory systems (e.g., associated with neuromuscular conditions, cystic fibrosis, spinal cord injury). (see [here](#), [here](#), and [here](#))

Structural factors

Social and economic disadvantage is both a cause and a consequence of disability. [Poverty, unsafe and insecure housing, social isolation, unemployment, discrimination, violence and abuse](#), are much more commonly experienced by people with disability in Australia and internationally. Disability is [more common among First Nations Australians](#) than the rest of the Australian population. First Nations Australians with disability face compounding disadvantage that already puts them at significant risk of poor health outcomes including in the COVID-19 pandemic.

Previous research has demonstrated that the disadvantage people with disability experience is directly related to poor physical and mental health outcomes relative to people without disability and is therefore avoidable (for example see [here](#), [here](#), and [here](#)). In Australia and internationally, COVID-19 has disproportionately impacted disadvantaged populations. The intersection of disability and disadvantage amplifies the risk for people with disability during the COVID-19 pandemic.

Systemic factors

Access to quality health care

A range of long-standing issues impact on access to health care for people with disability including suboptimal preventative health interventions, primary care and specialist and hospital care, many of which have been exacerbated by the pandemic (see [here](#) and [here](#)).

The Royal Commission for Violence, Abuse, Neglect and Exploitation of People with Disability found that people with cognitive disability experience [systemic neglect](#) in the health system. For example, in Australia, people with [intellectual disability are more likely to die prematurely](#) (median age of death 54 years compared to 81 years in the general population), with 38% of those deaths considered avoidable – double that of the general population.

Another concern for people with disability in the COVID-19 pandemic is the potential for discrimination or prejudice to affect their access to hospitalisation or critical care. [Discrimination or prejudice towards people with disability plays out in at least three ways](#). First, many people mistakenly assume that disability is necessarily linked to poorer health. However, in the absence of specific conditions that are associated with poor outcomes, being disabled does not lead to lower survival from COVID-19. Furthermore, many of the co-morbidities are unrelated to the ‘condition’ per se but are a consequence of social disadvantage. Second, triage decisions may be affected by assumptions that someone with disability will inevitably have a lower quality of life if they do survive COVID-19. And finally, implicit biases about the societal value of people with disability may influence decisions about access to critical care. It is important to emphasise the current ethical [consensus](#) is that considerations of long-term quality of life and societal value should not play a role in decisions about allocation of critical care.

There is some evidence to support the concern that these biases have an effect in practice. [Research from the UK shows that COVID-19 patients with intellectual disability](#) were more likely to receive oxygen therapy, but less likely to receive other forms of non-invasive respiratory support, to be ventilated or admitted intensive care, and more likely to die than age-matched controls. This was despite the fact that patients with intellectual disability who were admitted to hospital in this study were less likely to be smokers and had lower levels of co-morbidities such as cardiovascular or respiratory conditions and cancer. (NB. It is possible that some people with intellectual disability with co-morbidities were triaged out of hospital admission). Although equivalent data from Australia are not available, in an [Australian experiment](#) of the general public looking at allocation of ventilators in ICUs in a hypothetical scenario it was found that respondents were more likely to prioritise access to people without disability than those with a physical or intellectual disability.

What has happened so far in Australia?

We do not have a complete picture of what has happened to people with disability in Australia during the COVID-19 pandemic because of inadequacies in our data systems and, where data are available, the failure to make that information publicly available. Moreover, data reported publicly

only relate to the 470,000 participants in Australia's National Disability Insurance Scheme (NDIS). Eligibility for the NDIS is limited to those less than 65 years old at entry who have a severe, permanent disability and who are not receiving support from other systems, such as Accident Compensation Schemes. Even then, case numbers relate only to a subset of NDIS participants who use registered providers, introducing bias into these data in the form of underreporting.

Given evidence of the risks of COVID-19, people with disability were prioritised in the [National Vaccine Rollout](#). People with disability living in disability residential settings (commonly known as group homes) were included in Phase 1A and other people with disability with underlying conditions, with intellectual disability or serious mental illness were in phase 1B. On June 7 all [NDIS participants over 16 years were prioritised](#) for vaccination. However, there have been significant delays in the vaccine rollout to people with disability. For example, in-reach vaccination to group homes intended to start February 2021 was significantly delayed.

On [12 October vaccination prevalence](#) for people with disability and disability support workers lags behind both [national prevalence and prevalence in other priority groups including aged-care residents and workers and Australians older than 70 years](#). For example, nearly 90% of aged-care residents are now fully vaccinated compared to only 74% of residents of disability group homes. Despite being prioritised, NDIS participants aged 16 years and older are less likely to have been vaccinated than the general population. Vaccination prevalence for NDIS participants is 8% lower than the general population for at least one dose and 6% for full vaccination. Importantly, over 95% of Australians aged 70 years and older, who were also prioritised in Phase 1B, have had at least one vaccination compared to 76% for NDIS participants.

We do not know which groups of people with disability are less likely to be vaccinated. However, it is likely that the most marginalised people with disability, who are at greatest risk from COVID-19, including those with more complex and multiple disabilities and those who find it difficult access vaccination sites, lack family supports, and who are social isolated, are being left behind. Furthermore, some people with disabilities rely on substitute decision-makers to consent them for a COVID-19 vaccination and in some cases, the decision-makers are refusing to allow the person with a disability to be vaccinated. In other circumstances, when there is no obvious person who can act as a substitute decision-maker, it services have not obtained consent for vaccination.

What can be done to reduce risk for people with disability?

Mitigation of the risks of COVID-19 for people with disability requires a multi-pronged strategy. This strategy must aim to reduce risk of infection and poor outcomes if COVID-19 infection occurs. This requires measures that attend to individual factors, structural disadvantage, and systemic issues including barriers to access to vaccination and to health care and discrimination and prejudice.

Recommendations

1. Co-design of COVID-19 prevention and control strategies through respectful [community partnerships](#)
2. Improved data quality and reporting

3. Higher vaccination coverage targets for people with disability
4. All staff working with people with disability including support workers and allied health professionals fully vaccinated
5. Rapid escalation in vaccination for people with disability, their families and carers through better tailored vaccination strategies and targeted education and communication about the risks of COVID-19 and the effectiveness of vaccination, recognising the diversity of people with disability and intersectional disadvantage
6. Strategies to reduce SARS-CoV-2 transmission (refer to OzSAGE advice on [Safe Indoor Air \(Ventilation\)](#) through safe indoor air, ongoing mask use by workers, rapid antigen testing of workers (refer to OzSAGE advice [Creating Safe Workplaces during the Covid-19 Pandemic](#)), paid leave for workers who are either suspected or known to have COVID-19, ongoing infection control training, limitations on worker movement, updated outbreak management guidelines, contact training guidelines and training for services that support people with disability, people with disability, and family and carers)
7. Prioritisation of a third vaccination dose for people with disability
8. Better support of people with disability with COVID-19 infection
9. Ensure people with disability are not de-prioritised in access to care because of ableist assumptions about their health, quality of life, and social utility.

Details of recommendations

1. Community partnerships

Strategies for COVID-19 prevention and control, including vaccination, must be developed in partnership with the disability sector and community. This includes Disabled People's Organisations that represent the diversity of disability (e.g., intellectual disability, hearing impairment, autism), children and adults with disability, and intersectional disadvantage and marginalisation experienced by people with disability – including First Nations communities, migrant and refugee communities, those experiencing homelessness or housing precarity (e.g. people living in boarding houses), young people in juvenile justice, prisoners, and those living in non-urban settings. Disability services, the NDIS and NDIS Quality and Safeguards Commission, and unions representing disability support workers also needed to be included. Family and carers organisations need to be engaged to reach children and young people with disability, and people with disability for whom family members are substitute decision-makers. Communication strategies should be co-designed and disseminated through advocacy groups, services, and local communities.

Misinformation must also be tackled, particularly in relation to autism where false narratives about the adverse consequences of vaccination may cause hesitancy.

Community champions in local communities should be identified. For example, this could include champions from service organisations that play a primary role in assisting children and young people with disability and their families in rural and regional areas.

Organisations must be resourced to do this work.

2. Improved data collection and reporting

There are ongoing problems with the quality of disability data and the reporting of that data. This contrasts with other countries where there is data on the outcomes for people with disability in the COVID-19 pandemic. For example, the [Office of National Statistics in the United Kingdom has linked Census data on disability with primary care, hospital, and death data](#) to identify COVID-19 infection and death data and is providing up to date information to inform action. Similarly, analyses of the [OpenSafely platform](#) of electronic health record data has revealed the high risks of COVID-19 infection and death for people with intellectual disability. These resources demonstrate that it is possible to develop this data infrastructure rapidly so that analyses can identify trends and patterns that require policy responses.

While the linkage of the NDIS data and the Australian Immunisation Register is commended, the findings must be regularly reported publicly and disaggregated by disability type, age, local government area, and among First Nations Australians and culturally and linguistically diverse NDIS participants. Evidence from people with disability, families and supporters, and health care and disability service providers about barriers to vaccination (e.g., access to vaccination facilities, families refusing vaccination) is essential. Data needs to be shared with the disability sector and community to understand the trends. This information is essential for community partnerships to target information and outreach effectively and to monitor progress accurately.

The NDIS participant and screened worker data must be linked to the COVID-19 infection and death data; the current system of reporting cases among NDIS participants and workers is an undercount.

To capture the rates of vaccination, COVID-19 infection, and death for people with disability who are not in the NDIS, it is necessary to link a range of other data sources including income and family support data and Census data to track outcomes in real time.

Data on outbreaks in settings where people with disability live, learn and work, must be collected and reported to better understand how transmission is occurring and how it can be prevented.

3. Higher vaccination targets for people with disability

Given the high risks for people with disability identified internationally, we recommend that consideration is given to setting an initial vaccination target of 90% full vaccination for people with disability aged 12 years and over by December 2021. Achieving this level of vaccination should be a condition for relaxation of restrictions and opening of borders. However, all efforts should be made to achieve as close to 100% of people with disability vaccinated.

Every effort should be made to ensure substitute decision-makers understand the importance of vaccination however alternative arrangements for consent may be required if they refuse consent for their family member with a disability. Similarly, when there is no substitute decision-maker provision should be made to obtain consent from the Office of the Public Advocate.

Younger children with disability should be prioritised for vaccination when vaccines are approved for children under 12 years of age.

It must be an aspiration to maximise vaccination rates among all people with disability not only NDIS participants even though it is only possible at the moment to calculate vaccination prevalence for NDIS participants.

4. All disability workers are fully vaccinated

Given the risks to people with disability, we recommend that governments ensure that all staff that come into direct contact with people with disability are fully vaccinated. This should be supported by a dedicated communications strategy that directly addresses the concerns of workers and paid leave for workers to be vaccinated. For example, Victoria and NSW have introduced compulsory vaccination for disability workers and other States and Territories are likely to follow. In achieving full vaccination of the workforce, governments must protect against reductions in support for people with disability if workers unwilling or unable to be vaccinated leave the workforce.

5. Rapid escalation of vaccination among people with disability

As NSW, ACT and Victoria remove temporary public health restrictions with high COVID-19 caseloads, they must rapidly escalate vaccination rates among people with disability. However, vaccination rates lag population vaccination rates in other states (by 6-11% for fully vaccinated) and people with disability in those States and Territories are at risk if an outbreak occurs and when their borders open to NSW and Victoria. This requires:

- in-reach vaccination for people who are unable to leave their home because of their disability, or for whom vaccination hubs, GP practices and other sites may be inaccessible or overwhelming
- accessible vaccination sites including physical accessibility, visual aids for people with lower literacy, Auslan or clear written instructions for people with who are Deaf and/or Hard at Hearing, transparent masks to enable communication, sensory friendly settings, and Easy English material.
- a single phone number and accessible website so that there is 'no wrong door' when booking vaccination
- specialised staff who can provide information and organise appointments, such as the [Disability Liaison Officers in Victoria](#)
- mobile disability vaccination units that can travel to regional, rural, and remote settings
- access to sedation for people with disability for whom medical procedures are frightening or have disabling needle phobia (e.g., sometimes experienced by people with autism)
- compilation of innovative approaches to achieving vaccination and development of resources for these to be implemented more broadly, coordinated through central helpline, websites and/or Disability Liaison Officers

6. Strategies to reduce transmission risk

Strategies that are now known to reduce virus transmission risk should be implemented. These include:

- *Safe indoor air* – People with disability may live, learn, work, and congregate in indoor environments and it is critical that attention is given to the ventilation of those spaces. Disability service providers should ensure that all shared spaces are well ventilated. Where ventilation is poorer (e.g., corridors, amenities) they may need additional ventilation in the form of supply and exhaust fans and/or portable HEPA filtration units. Disability service providers should invest in CO₂ monitors to identify where transmission risk is high and where other measures may need to be put in place (Refer to OzSAGE advice on [Safe Indoor Air \(Ventilation\)](#) for recommendations on risk reduction). Oversight of this for NDIS-registered services should be done by the NDIS Quality and Safeguards Commission in conjunction with public health units.
- *Compulsory mask use by workers* – COVID-19 is an airborne disease, and the use of masks is integral to reduce transmission and to offer some protection if there is any breakdown of other controls. Basic cloth masks and surgical masks contribute to a reduction in transmission of COVID-19. The effectiveness of mask use is increased when masks fit snugly around the wearer's face. Workers should be trained in how and when to use them, and usage and restocking should be monitored. At a minimum, where workplaces are located in areas with community transmission of COVID-19, masks should be worn whenever workers are located indoors. Appropriate Personal Protective Equipment should be provided to disability support workers and people with disability free of charge. Refer to OzSAGE advice on [Community mask use](#) for further information.
- *Rapid antigen testing of workers* – Where practical, allowing for logistics, organisation and cost, protocols for Rapid Antigen Testing (RAT) in this sector are best developed with workers, laboratories, and public health units. RAT should be free to all staff and conducted several times per week. Refer to [OzSAGE advice Creating Safe Workplaces during the Covid-19 Pandemic](#).
- *Paid leave for workers* – Approximately half of disability workers do not have access to paid leave. There is a strong risk that some may continue to go to work with COVID-19 symptoms as they cannot afford to [lose pay](#). Income support/sick pay while testing or isolating should be available for all Disability Support Workers.
- *Limitations on worker movement* – Aged-care and disability-care outbreaks have been driven by worker movement between facilities. It is recommended that workers should be restricted to working in no more than two residential facilities.

- *Update CDNA national guidelines for the prevention and management of COVID-19 outbreaks in disability residential services* – currently these [guidelines](#) do not adequately consider airborne transmission and the emergence of more infectious variants of concern.
- *Contact tracing guidelines* – people with disability and supporters and services have already been doing their own contact tracing. Guidelines on how to support them to do this effectively should be developed.

7. Early access to third doses of COVID-19 vaccines

The initial conditions for a third dose listed by the [Commonwealth Government](#) is relatively restricted and applies to those likely to have impaired vaccine responses rather than high risk groups. We recommend that as per initial National Rollout prioritisation, people with disability are prioritised in future strategies for 3rd doses as they remain at much higher risk of serious disease and death after vaccination (e.g., people with [Downs Syndrome and neurological conditions](#)).

8. Better support for people with disability with COVID-19

Without appropriate support in place some people with disability may not receive the essential care they need (e.g., self-care needs, communication supports) if they are hospitalised. It is therefore essential that people with disability who rely on disability support workers, family members and supporters can continue to be supported by someone while in hospital with appropriate infection control and PPE.

There also needs to be specific investment in health services to treat people with disability with COVID-19 in their homes, supported by their familiar disability support workers, family members and other supporters.

9. Ensure people with disability are not de-prioritised in COVID-19 and non-COVID-19 health care

As COVID-19 numbers in Australia increase, it is likely that access to health care will be restricted, and difficult decisions will need to be made about allocation of routine and life-saving health care. Triage guidelines must be reviewed to ensure they do not inadvertently discriminate against people with disability, including children and young people with disability, because of assumptions about health, quality of life, and social utility. Triage decisions should not further entrench inequities related to having a disability. In order to be fair, guidelines should state [explicitly that disability alone](#) must not be used as a potential reason to de-prioritise a patient for critical care.

Resources

Australian Government Department of Health. Information for people with disability about vaccines. <https://www.health.gov.au/initiatives-and-programs/covid-19-vaccines/disability-sector/people-with-disability>

Australian Government Department of Health. Information for disability support workers about vaccines. <https://www.health.gov.au/initiatives-and-programs/covid-19-vaccines/disability-sector/workers>

Australian Government Department of Health. Information for disability service providers about vaccines. <https://www.health.gov.au/initiatives-and-programs/covid-19-vaccines/disability-sector/service-providers>

Australian Government Department of Health. Coronavirus (COVID-19) advice for people with disability. <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/advice-for-people-at-risk-of-coronavirus-covid-19/coronavirus-covid-19-advice-for-people-with-disability>

Australian Human Rights Commission. Guidelines on the rights of people with disability in health and disability care during COVID-19. 2020. <https://humanrights.gov.au/our-work/disability-rights/publications/guidelines-rights-people-disability-health-and-disability>

NDIS Quality and Safeguards Commission coronavirus (COVID-19) information. <https://www.ndiscommission.gov.au/resources/coronavirus-covid-19-information>

United Nations. Policy Brief: A Disability-Inclusive Response to COVID-19. May 2020. https://www.un.org/sites/un2.un.org/files/sg_policy_brief_on_persons_with_disabilities_final.pdf

United Nations Human Rights. COVID-19 and the rights of persons with disabilities: Guidance. 2020. https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf