Australian Government
National Health and Medical Research Council

NHMRC

National COVID-19 Health and Research Advisory Committee*

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Advice 27: Rapid review on the impact of COVID-19 on people with disability

Focus

The Chief Medical Officer has requested a rapid review that:

- summarises the published data on the infection, vaccination, mortality and morbidity rates for people with disability associated with COVID-19
- identifies any factors (clinical and non-clinical) that might contribute to higher infection and/or mortality rates among people with disability
- assists with understanding the barriers to uptake of COVID-19 vaccinations among people with disability.

Note

This report is point in time and may need further updating as more evidence is available.

This report was developed with the assistance of a working group of the National COVID-19 Health and Research Advisory Committee (NCHRAC), chaired by Associate Professor Lorna Hallahan, with input from external experts: Dr Jacqueline Small (Developmental Paediatrician, Sydney), Professor Gwynnyth Llewellyn (University of Sydney), Professor Anne Kavanagh (University of Melbourne) and Professor Julian Trollor (UNSW).

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Key points:

- The COVID-19 pandemic has amplified the existing health inequalities that people with disability experience.
- People with disability have a greater risk of acquiring COVID-19 compared with people without disability, due to clinical and non-clinical factors.
- Once infected with COVID -19, people with disability have a higher incidence of serious health consequences and mortality.
    - People with intellectual or developmental disability, Down syndrome, or psychosocial disorders appear to have worse outcomes than people with other disabilities.
- Vaccination should be prioritised for people with disability who are at increased risk of infection and serious adverse health outcomes from COVID-19, such as people:
    - with comorbidities that are associated with adverse COVID-19 outcomes (i.e. diabetes, obesity, chronic kidney disease, chronic neurologic disorders, active malignancy, moderate to severe liver disease, or use of immunosuppressive medications)
    - who use psychotropic medication
    - who are reliant on assistance from support care workers or family for intimate personal care and other activities of daily living
    - who live in congregate settings or have shared care arrangements where support care workers attend to multiple clients across a number of locations.
- Families and support care workers who care for people with disability who are at increased risk of transmission and serious adverse health outcomes from SARS-CoV-2 should be prioritised for vaccination.
- Successful vaccination strategies include:
    - accessible bookings in a variety of formats with telephone-based supports
    - dissemination of information through trusted channels and networks such as Disability Representative Organisations or local community groups
    - consideration of how people with disability in rural and remote areas will access vaccination services (given the challenges they already face in accessing primary care)
    - physical accessibility that considers people with physical, sensory or intellectual disabilities; in some instance in-reach strategies may be more appropriate
    - vaccination-service staff that are trained in assisting and supporting people with disabilities
    - space for caregivers, service animals, greeters, Auslan interpreters, privacy curtains, and low-sensory sites or low-sensory hours.
- As states and territories reach 70% and 80% double vaccination milestones and restrictions ease, there is concern that people with disabilities will be vulnerable to serious health outcomes due to lagging vaccination rates.

Approach to the review

An initial PubMed search sought to identify literature that examined if there were factors that increased the susceptibility of people with disability to COVID-19 infection, as well as evidence on once infected what was the severity of outcomes and mortality rate compared with the general population. A second search for literature was conducted on SARS-COV-2 vaccination programs/strategies for people with disability to identify if any barriers or enablers have been identified in other high-income countries.

Snowballing was used to identify additional relevant literature and data.

The evidence identified through both searches was sparse and many authors commented that these issues required further research. Additional information was gained through consultation with relevant experts in the field as well as considering grey literature and government reports. Data published on government and non-government websites was scanned for vaccination rates for people with disability.

Given the length of time to conduct the review a quality appraisal of the included studies was not conducted. The outcomes of the search have been synthesised into a narrative to capture overarching themes and lessons learned from international experiences of the SARS-CoV-2 pandemic and its impact on people with disability.

Definitions.

The broadest definition for 'people with disability' was adopted to include physical, intellectual, sensory and psycho-social disability as per the Australian Institute of Health and Welfare (AIHW) report, *People with disability in Australia 2020*.[2]

Sensory (e.g., sight, hearing, speech)
Intellectual (e.g., difficulty learning or understanding)
Physical (e.g., breathing difficulties, chronic or recurrent pain, blackouts or seizures, incomplete use of limbs)
Psychosocial (e.g., nervous or emotional conditions, mental illness, memory problems, social or behavioural difficulties)
Head injury, stroke or acquired brain injury
Other (restrictions in everyday activities due to other long-term conditions or ailments)

No age limit was placed on the search for literature. Children and young people were considered to be under 18 years.

Residential settings: All form of residential settings were considered, community and congregate. Congregate settings are places where a number of people reside, meet or gather in close proximity for either a limited or extended period of time.

Context for the review

Australia has experienced a different pandemic to that in Europe, the United States (US) and United Kingdom (UK) due to the lower levels of community transmission of COVID-19. This

presents the opportunity to learn from others and understand the risks faced by people with disability and ensure vaccination policies follow a human-rights approach to prioritise access to those most vulnerable who are at greatest infection risk and severe health outcomes.

The World Health Organisation (WHO) *World Report on Disability* (2011) states that people with disability are more likely than the general population to have health issues, compromised immunity, increased risk of morbidity, comorbidities and more likely to die from preventable causes, and are female.[3] People with disability are a diverse group, and the risks, barriers and impacts faced by them will vary in different contexts according to, among other factors, age, gender identity, type of disability, ethnicity, sexual orientation, and migration status. The drivers for the health disparities are complex in origin, and are, at least in part, an outcome of structural inequities in opportunity, education, employment, housing, healthcare access and income.[4] They affect diverse groups of people with disability disproportionately, resulting in complex layers of disadvantage.

The COVID-19 pandemic has amplified the existing health inequalities experienced by people with disability by: increasing the risk of poor outcomes due to associated comorbidities; reducing access to routine health care, support and rehabilitation; and public health measures adversely impacting on physical and emotional wellbeing.[5]

In March 2020, the WHO released a technical document titled, *Disability considerations during the COVID-19 outbreak*, which outlined the increased risks faced by people with disability.[6] This document provides advice on actions and protective measures that could be implemented by key stakeholders to mitigate the impact of COVID-19.

Summary of evidence

The literature search revealed there is a lack of empirical research on the experiences of people with disability in COVID-19. Most of the publications identified were commentaries, opinion pieces or case reports on intellectual and developmental disabilities, mood disorders, and mental health issues. There is also a lack of evidence on the full range of disabilities and no evidence about the compounding factors related to health disparities. Limited data was identified on children and young people.

Factors (clinical and non-clinical) that may contribute to greater risk of infection to SARS-CoV-2 for people with disability compared to the general population

Many people with disability are at increased risk of contracting COVID-19 due to:

- clinical factors; i.e. underlying physical or medical conditions that increases susceptibility to infection and adverse outcomes; and
- non-clinical factors that affects their access physical, mental and social wellbeing.

Both these factors are attributable to, and amplified by, poor social determinants and barriers to accessing healthcare.[7]

Clinical factors

Adults intellectual and developmental disabilities (IDD)

There is evidence that people with learning disability are twice as likely to contract COVID-19 infection.[8] A number of international studies reveal that COVID-19 positivity rates were approximately 1.28 times higher for adults with IDD compared with the general population; for people with Down syndrome it was slightly higher again: 1.42.[9] Those receiving intellectual disability services had a lower-case rate of COVID-19, but had a higher case-fatality rate (2.8 times).[10,11] They were also more likely to be under 30 and less likely to be over 80.

Individuals with Autism Spectrum Disorder (ASD) share a physiological and genetic vulnerability for COVID-19 infection. Increased levels of pro-inflammatory cytokines have been documented in individuals with ASD. The tendency towards a pro-inflammatory state among individuals with ASD may place them at higher risk for even more severe symptoms once this virus is contracted, including a rare multi-systemic inflammatory syndrome evident in children.[12]

Mood disorders

Mature adults with psychiatric conditions are particularly vulnerable to COVID-19 due to normal age-related decline in the immune system and comorbid conditions. Comorbid conditions such as associated polypharmacy, hypertension, diabetes mellitus, chronic renal failure, and chronic obstructive pulmonary disease can contribute to an increased vulnerability to illness and poor health outcomes in this population.[12]

People with pre-existing mood disorders reported a higher incidence of COVID-19 infection (odds ratio (O.R)= 2.02). People with dementia and Parkinson's disease also have a higher susceptibility to COVID-19 infection and severity of illness.[13]

Non-clinical factors

Capacity and ability to adhere to public health measures and non-pharmaceutical interventions

Non-pharmaceutical interventions implemented to limit the spread of COVID-19 present a number of difficulties and can have a negative impact on some groups of disabled people.

- Use of personal protective equipment (PPE) and appropriate hand hygiene is challenging for people with physical disabilities and cognitive impairment to implement. The use of masks is a barrier to communication for people with hearing impairments who rely on lip-reading.[14]
- Social distancing is challenging for those reliant on touch (e.g. for those who are blind or deafblind) or physical support.[15] Adults with intellectual disability and severe neurocognitive disorders, such as dementia, also have difficulty adhering to social distancing.[12]
- Isolation and lockdown measures have a differential impact by disrupting routine, socialising, the ability to function or to address additional health needs.[8] This can adversely affect mental health and be even more debilitating.

- Interruption of services and schooling restricts access to regular health care, rehabilitation, medicines, equipment and education. It also places more pressure on families, if they have them, for support.[16]
- Lockdown measures and isolation can also place some vulnerable individuals at risk of abuse and domestic violence.[5]

Residential and congregate settings

Australia's previous experience with influenza has shown that infection can spread rapidly in congregate living setting, such as residential aged care facilities. The same precautions need to be applied to people with disability in congregate care settings to reduce their risk of exposure to COVID-19. Particularly those living in high-density residential settings who are at higher risk.[16,17] The risk of transmission of COVID-19 is further increased for people with limited mobility, severe mental health illness due the implementation of infection control practices being more challenging.[13,18,19]

The same considerations need to be given to reducing the risk of exposure in other congregate environments, such as supported employment, day care centres and prisons/correctional facilities (where people with disability, particularly people with intellectual and psychosocial disability, are overrepresented).[20]

Reliance on personal support

People with disability that require the physical assistance for personal care and activities of daily living, such as eating and washing ,from family and careers are at increased risk of social transmission.[8,16,21] This risk is increased when support care workers are required to work with multiple clients across a number of locations.

Support care workforce

In Australia, support care workers were ill-equipped to use appropriate PPE in settings where a client in a residential setting was infected with COVID-19. A survey of support workers in June 2021 revealed that 22% had not received any infection prevention and control training. Of those who had, 48% wanted more. It was also revealed that many services did not have the necessary PPE nor had a back-up or surge workforce been identified to provide sufficient care.[22]

The casual work force structure in the disability sector offers no incentives or financial support for carers to stay at home if they suspect that they have COVID.[23]

Availability of accessible public health information

Information on COVID-19, public health measures and available services needs to be provided in accessible formats for people with sensory, cognitive or intellectual impairments.[14,19] Communication on COVID-19 needs to occur through trusted channels to people with disability and their family or carer, such as Disability Representative Organisations (DRO) or local community organisations.

Risk of experiencing serious health consequences due to COVID-19 (e.g. requiring hospitalisation) for people with disability

If symptomatic, people with disability were three times more likely to be hospitalised due to their risk of complications and/or difficulties in accessing care in the home.[24] Their increased

risk of serious health consequences is attributed to their higher prevalence of comorbidities compared to their non-disabled counterparts, especially in younger age groups.[18,22,24]

Previous NCHRAC advice identified that people with diabetes, chronic kidney disease, obesity, chronic neurologic disorders, active malignancy, moderate to severe liver disease, or use of immunosuppressive medications are at risk of severe illness or death if infected with SARS-CoV-2.[*] Pre-existing mental and neurological disorders, including mood disorders, were noted in the literature to be related to a higher incidence and worse prognosis of COVID-19.[13]

The severity of health outcome for some people with disability is compounded by intersectional factors such as poverty, poor health literacy, homelessness, poor education, and communication barriers which impact on access to health care. Overseas, to manage hospital demand, health facilities implemented triage for receipt of treatment and support for COVID-19 that resulted in people with disability being less likely to receive the critical care they required.[13,18,22]

During the COVID-19 pandemic, adults with disability have experienced significantly poorer mental health and were concerned about access to needed health care services at two times that of adults without disabilities. Adults with disability were significantly more likely, than those without disability, to report social determinants of health stressors (e.g. accessing needed health care services; having enough food), conflict or stress within the household, and emotional or physical abuse. All these factors contribute to worsening mental health and adverse health outcomes.[19]

Based on UK data, people with disability were more likely: to be hospitalised if symptomatic (adjusted proportional reporting ration (PRR) 3.0 95% 1.07-8.43); to experience current symptoms of psychological distress (PRR 1.15, 95% CI 1.05-1.26) and to report being lonely (PRR 1.75, 95% CI 1.46-2.09) compared to non-disabled people.[24]

A large population-based cohort study in Scotland found COVID-19 infection rates for people with IDD were almost twice the level of people without IDD, and they had worse outcomes once infected, particularly those under 65 years.[25] Adults with intellectual disability often have higher rates of asthma, diabetes, COPD, dementia, CP, epilepsy, mental illness and addiction.[9,14]

Living in congregate settings placed people with disability at greater risk of severe COVID-19 outcomes compared to general population.[26] This risk was greater for those with intellectual disability and for adults under 75 years of age.[10,27-29]

Poorer outcomes for people with disability was also, in part, due to delays in healthcare workers and carers recognising clinical deterioration particularly when the individual has issues with comprehension and communication.[21,30] Care issues included delays in identifying that a person is ill, recognising further deterioration, and accessing and receiving appropriate medical care. People with intellectual disabilities, though presenting with severe

[*] NCHRAC Advice: Risk stratification of population groups in the context of COVID-19, 16 June 2020

signs, were less likely to get respiratory treatment or access to an ICU, and were more likely to die from COVID-19.[31]

Mortality rate of SARS-CoV-2 for people with disability

Recent data from the UK highlight that people with IDD die from COVID-19 at a rate six times more than the general population in 2020.[32] Further analysis revealed that 65% of those who died from COVID-19 had a mild or moderate disability.[33] This is higher than the earlier calculations analysis by Public Health England that people with IDD were three and four times more likely to die of COVID-19.[8] Currently only those with severe or profound IDD and adults with Down syndrome are on the priority list for vaccination in the UK.

A case series looking at deaths of people with mild to profound intellectual disability provided insight into possible risk factors for COVID-19 related mortality. Comorbidities varied between the mild and moderate to profound intellectual disability groups however, epilepsy, dysphagia and dementia was associated with premature mortality.[16] The risk of mortality for people with disability, compared to people without disability, living in congregate settings was elevated compared to those in living in household settings.[5]

These results mirror data from Canada and US. In Ontario, mortality rates from COVID-19 were observed to be higher for adults with IDD (Relative Risk (RR) 2.23 (95%CI: 1.86,2.67)) than for those without. The mortality rate for people with Down syndrome was 6.59 times higher (95%CI: 4.51,9.62) than those without disability.[9] The study of New York residents found that in children and adults with IDD the case-fatality rate was 38%. Factors observed to increase the risk of death were Down syndrome, heart disease, kidney disease and density of the residential setting.[17]

In all of these studies, mortality from COVID-19 was observed to occur at a lower median age group compared to people without disability, although increasing age increases the risk of mortality.

A systematic review of studies from a number of countries revealed that the presence of any mental health disorder was associated with the risk of COVID-19 mortality (odds ratio (OR) 2.0 95% CI 58-2.54; I^2 92.66%), in particular psychotic and mood disorders, and exposure to antipsychotics and anxiolytics. The initiation of antipsychotic and anxiolytic drug treatments before contracting COVID-19 was associated with severe COVID-19 outcomes. The increased risk of COVID-19 mortality was suggested to be due to biological processes, such as immune-inflammatory alterations, including immunogenetic abnormalities, raised cytokine concentrations, autoantibodies, acute-phase proteins, and aberrant counts of leukocyte cell types, which characterise psychiatric disorders.[16]

An analysis of deaths in children and young people due to COVID-19 in the first wave of the UK pandemic observed that teenagers were more likely to be affected than younger children. Complex neurodisability was noted to be the highest risk comorbidity and comprised of 52% of all deaths. Although the absolute risk of death for children and young people due to COVID-19 is extremely low, neurodisability combined with respiratory conditions was thought to present a particularly high risk.[1]

Other risk factors identified in the international literature associated with mortality from COVID-19 for people with disability were chronic neurological disorders such as dementia (OR = 2.16, 95% CI = [1.40, 3.33], P = .001), cerebral-vascular disease (OR = 2.3; 95%CI 1.2, 4.7; p = 0.017), and stroke (OR = 1.93, 95% CI = [1.29, 2.88], P = .001).[34 35 36]

COVID-19 vaccination for people with disability in Australia

Principles for prioritising access to vaccination

Prioritisation of access to COVID-19 vaccines should follow a human-rights approach, considering: (1) infection risk and severity of pre-existing diseases; (2) social vulnerabilities; and (3) potential financial and social effects of ill health.[38]

Formal and informal caregivers of people with disability should be considered as a priority - in order to avoid disruption of key services and support that many people with disability rely on to meet their basic needs.[18]

Australia's priority populations

The Australian COVID-19 vaccination policy identified preliminary priority populations for vaccination as:

- Those who have an increased risk, relative to others, of developing severe disease or outcomes from COVID-19, i.e. Aboriginal and Torres Strait Islander people, older people and people with specified underlying medical conditions.
- Those who are at increased risk of exposure and hence being infected with and transmitting SARS-CoV-2 to others at risk of severe disease or are in a setting with high transmission potential, including disability support workers or people with disability who rely on support.

Data on vaccination rates

Some international (UK and Canada) and Australian data has been obtained on the vaccination of people with a disability. The limitations of the data obtained do not allow for a direct comparison of Australia's COVID-19 vaccination rates for people with disabilities to other nations; however the data obtained offers some insights. The limitations are discussed in detail below and the data is available in Appendix 1.

United Kingdom

In the UK, OpenSafely, a data platform covering around 40% of GP practices in England, reports regular updates on data relating to COVID-19 vaccinations by IDD based on general practitioner registration. Tables 6-11 in Appendix 1 show 1st, 2nd and 3rd (where available) dose vaccination rates for priority populations including those with various intellectual or developmental disabilities, residents in care homes, people with psychosis, schizophrenia, or bipolar and those who are shielding (defined by those in a high risk category for developing complication from COVID-19).

For older adults with intellectual disabilities vaccination rates are at least 90% or more and are now similar to those found in the general population. Vaccination rates for people with psychosis, schizophrenia, or bipolar disorder have vaccination rates lower that those without the conditions, but exceeded 80% for those aged 50-69 and 90% for those aged 70+.

Vaccination rates for those in a residential home, hospice or staffed home exceeded 94% for those aged 65+ (Table 11, Appendix 1). Residents of younger adult care homes are not part of a priority group in the UK; however they are likely to be categorised in a subsequent priority groups due to their recognised vulnerability. As of 27 July 2021, 92.7% of residents in younger care homes have received their first COVID-19 vaccine dose and 88.5% received their second dose.[39]

Canada

National Canadian vaccination data was not able to be obtained; however, a detailed breakdown of vaccination rates of priority populations was publically available for Ontario (Canada's most populous province).[40] A breakdown of 1st and 2nd doses for various conditions including intellectual or developmental disability and severe mental illness for 12-64 year olds and 65 years plus is available in Table 12, Appendix 1. For intellectual or developmental disability, both first and second dose vaccination rates are on par (only slightly below or exceeding) individuals with none of the priority group conditions. Those with severe mental illness did have lower vaccination coverage.

Australia

In Australia, on 14 September 2021, only 58.7% (1st dose) and 39.9% (2nd dose) of National Disability Insurance Agency (NDIA) participants aged 16 and up had received a COVID-19 vaccine (Table 1, Appendix 1). While, 69.1% had received a single dose and 43.9% of the general population had received 2 doses.[41] These figures demonstrate that NDIA participants have lower vaccine coverage than the greater Australian population. This disparity may be more severe considering that NDIA participants only represent a fraction of people with a disability in Australia.

As states and territories reach 70% and 80% double vaccination milestones and restrictions ease, there is concern from the sector that unvaccinated people with disabilities will be impacted due to lagging vaccination rates and vulnerability to poor outcomes.[42] This concern is being felt also in the UK, with the removal of restrictions resulting in 24% of survey participants with an intellectual disability and 30% of carers not feeling safe enough to go to all the places they used to.[43]

Vaccination of disability support workers is an important consideration in the wellbeing of people with a disability in Australia. In the UK, a nation-wide survey revealed that 80% of people with intellectual disabilities and their family members/support workers think that support workers should have to have the COVID-19 vaccination to work in the sector.[43]

Factors that affect vaccination for COVID-19 of people with disability

Inhibiting factors and barriers

In the USA, adults with disability have reported more difficulties obtaining a COVID-19 vaccine than persons without a disability.[15]

The draft report for Public Hearing 12 of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability titled, *The experiences of people with disability, in*

the context of the Australian Government's approach to the COVID 19 vaccine rollout, outlines 17 findings regarding COVID-19 vaccination of people with disability in Australia.[44]

Additional barriers identified in the literature and media are listed below:

- **Hesitancy:** A study in the UK involving adults with intellectual disability found that willingness to take the COVID-19 vaccine is high.[45] In the USA adults with a disability had a lower likelihood of having received COVID-19 vaccination, despite being less likely to report hesitancy about getting vaccinated.[15] Although there is no evidence that vaccine hesitancy is a major contributor to vaccine uptake by people with disabilities in Australia, Finding 13 of the Draft Report of Public Hearing 12 states that a lack of clarity in communication, uncertainly and confusion may have contributed to vaccine hesitancy among some people with disability.
- **Education and information:** People with disability may be less likely to be able to get appropriate, accessible, timely information as they rely on carers for all health care inputs.[21] In the UK, a national research project that has interviewed adults with IDD found that television news is the most common way (69% of people with IDD and 56% of family carers/support workers) to find information on COVID-19 rule changes.[43]
- **Access barriers:** In the USA, reported barriers for vaccination included getting an appointment online, not knowing where to get vaccinated, getting to vaccination sites, and sites not being open at convenient times.[15] In Australia, difficulties in finding vaccination bookings have been reported for both adults and children with disabilities.[46,47] Needle phobias and a lack of reasonable adjustments to clinics are also key factors inhibiting vaccination of people with intellectual or learning disabilities.[48]

Vaccination programs - enabling factors

The WHO and UNICEF have published a policy brief on *Disability considerations for COVID-19 vaccination*. This brief includes a series of suggested actions for government as well as considerations for a barrier-free vaccination sites. Factors than enable disabled people to access vaccines have also been considered in the media and literature.[7,21,49]

The following factors and considerations will go towards addressing the issues raised in the Royal Commission's draft Commissioners' report on public hearing 12 *The experiences of people with disability, in the context of the Australian Government's approach to the COVID 19 vaccine rollout* (27 September 2021)[44] and the Statement of Concern (26 March 2020)[50]:

- **Minimise hesitancy:** Maximise willingness of people with disabilities to participate in COVID-19 vaccination by providing accessible information on COVID-19 and local restrictions. Dissemination of information via trusted channels and networks is important as people with disability first to their peak organisations or local community for information.[51]
  A study of people with intellectual disability in the UK found that knowledge of local pandemic-related restrictions and information sourced from television bulletins was associated with increased willingness to be vaccinated.[45] Accessible communications

should include information that specifically focuses on vaccine disability- and co-morbidity-specific safety information.[7]

- **Accessible booking:** Vaccination bookings should be offered in multiple formats. For online bookings, websites should be accessible and offer telephone support. Burden of proof for disability status (where applicable for eligibility) should be minimised as much as possible.[7]
- **Physical accessibility:** Vaccination sites should have accessible entrances with clear signage indicating accessibility and how to request accommodations (wheelchairs, tactile guidance, etc.).[7] Where possible, home/site visits should be offered where transportation to GP/vaccination hubs is not practicable (such as residential and congregate living settings or for individuals who are high-risk, have difficulty wearing a mask or seeing others get needles).[52] Information on how to arrange home/site visits should be communicated with carers and disability service providers/networks. Vaccination initiatives such as collaboration with the Royal Flying Doctor Service for regional and rural Australia should incorporate disability-friendly processes.
- **Environmental accessibility:** Accessibility of vaccination sites can be enhanced by expedited lines for those with disabilities, staff trained in assisting and supporting people with disabilities, actively listening to self-expressed preferences of people with disability and their carers, space for caregivers and service animals, greeters to assist, availability of Auslan interpreters, privacy curtains, and low-sensory sites or low-sensory hours.[7,49,52] In a trial of a COVID-19 accessible vaccination pathway for people with learning disabilities and autism found that reasonable adjustments and techniques such as stakeholder engagement and pre-screening, limits on sound, smells and room access to others resulted in a high percentage of people with disabilities being successfully vaccinated. This kind of accessible clinic requires learning disability nurses' specialist skills.[48] The UK's National Health Service training for volunteers and clinicians supporting people with learning disabilities and autism is included in Appendix 2.

Data Limitations

This rapid review has identified that there is limited public health data on COVID-19 vaccination of people with disability in Australia. Primary health care data at point of vaccination – general practice – does not include information on disability.

National Disability Insurance Scheme (NDIS) data only represents approximately 10% of people in Australia with disability. In addition, only registered NDIS providers are required to report to the Commission. A breakdown of NDIS demographics is included in Appendix 1.

NDIS participants who manage their own NDIS funded supports may use providers who are not registered. Participants and unregistered providers are not required to report to the National Disability Insurance Scheme Quality and Safeguards Commission. Also, demographic data relating to the participants or workers infections themselves is not collected. The NDIS Commission does not systematically collect the vaccination status of participants or workers, as they have no legal authority to request health information.

Limited international data on the vaccination of people with disability has been sourced and is available in Appendix 1. COVID-19 vaccination data by disability status is not readily available; however data has been sourced from the UK and Canada. Unfortunately, not all of the data is national and does not capture all types of people with disabilities (physical, intellectual, sensory and psycho-social disability).

Other considerations

- Mandatory vaccination of disability support workers.
- Harder to reach populations, such as rural and remote, Aboriginal and Torres Strait islanders, people from culturally and linguistically diverse backgrounds would benefit from strategies and information developed in partnership with trusted sources such as local community organisations or DROs; Engagement of these stakeholders will improve reach.
- Vaccination strategies need to account for residential settings of people with disability in Australia. Most (96%) live at home or in the community, this includes 87% of people with severe or profound disability.[2]

Attachments

Appendix 1: COVID-19 vaccination rates for people with disability in Australia and overseas

Appendix 2: NHS training for volunteers and clinicians supporting people with learning disabilities and autism

References

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APPENDIX 1: COVID-19 vaccination rates for people with disability in Australia and overseas

Australia

National Disability Insurance Scheme (NDIS)[1]

COVID-19 Vaccinations – records based on data matching between NDIS and the Australian Immunisation Register (AIR)

NDIS Demographics

- About 157,000 people received open employment services under the National Disability Agreement (NDA) in 2018–19. Around 339,000 people were active participants in the National Disability Insurance Scheme (NDIS) at 31 December 2019.
- 4 in 10 (40%) active NDIS participants are aged 14 and under. 7.6% (or 20,500) identify as Aboriginal or Torres Strait Islander people.
- The most common disability groups are autism (31%), intellectual disability (23%, including those with Down syndrome) and psychosocial disability (9.1%).
- 28% have a low level of function, 44% have a medium level of function and 27% have a high level of function, in terms of level of disability.
- 3,900 are younger people in residential aged care (aged under 65) (NDIA 2020).

Participant data matching as at midnight: 14 September 2021
AIR numbers as at midnight: 14 September 2021

Table 1: Total vaccines reported for NDIS participants by dose and state or territory

Jurisdiction	Total NDIS participants that have received dose 1	Total NDIS participants that have received dose 2	Total people who have received at least one dose	**Total Doses**	*Total NDIS participants aged 16 and over*	Percentage who have received at least one dose	Percentage who have received 2 doses	Change in total people who have received at least one dose since last report	% Change in total people who have received at least one dose since last report	% Change in total people who have received two doses since last report
NSW	20,189	34,875	55,064	89,939	83,328	66.1%	41.9%	+595	+1.1%	+1.8%
VIC	13,756	30,002	43,758	73,760	70,664	61.9%	42.5%	+434	+1.0%	+1.3%
QLD	8,006	18,476	26,482	44,958	52,175	50.8%	35.4%	+250	+1.0%	+1.4%
WA	3,452	8,311	11,763	20,074	24,865	47.3%	33.4%	+135	+1.2%	+1.6%
SA	2,917	8,635	11,552	20,187	22,255	51.9%	38.8%	+121	+1.1%	+1.3%
TAS	834	2,933	3,767	6,700	6,646	56.7%	44.1%	+32	+0.9%	+0.6%
ACT	790	2,589	3,379	5,968	5,025	67.2%	51.5%	+43	+1.3%	+2.0%
NT	300	1,001	1,301	2,302	2,568	50.7%	39.0%	+12	+0.9%	+1.6%
National	**50,244**	**106,822**	**157,066**	**263,888**	**267,526**	**58.7%**	**39.9%**	**+1,622**	**+1.0%**	**+1.5%**

Note: Total NDIA participant numbers obtained as of 30 June, 2021 (aged 16 and over).

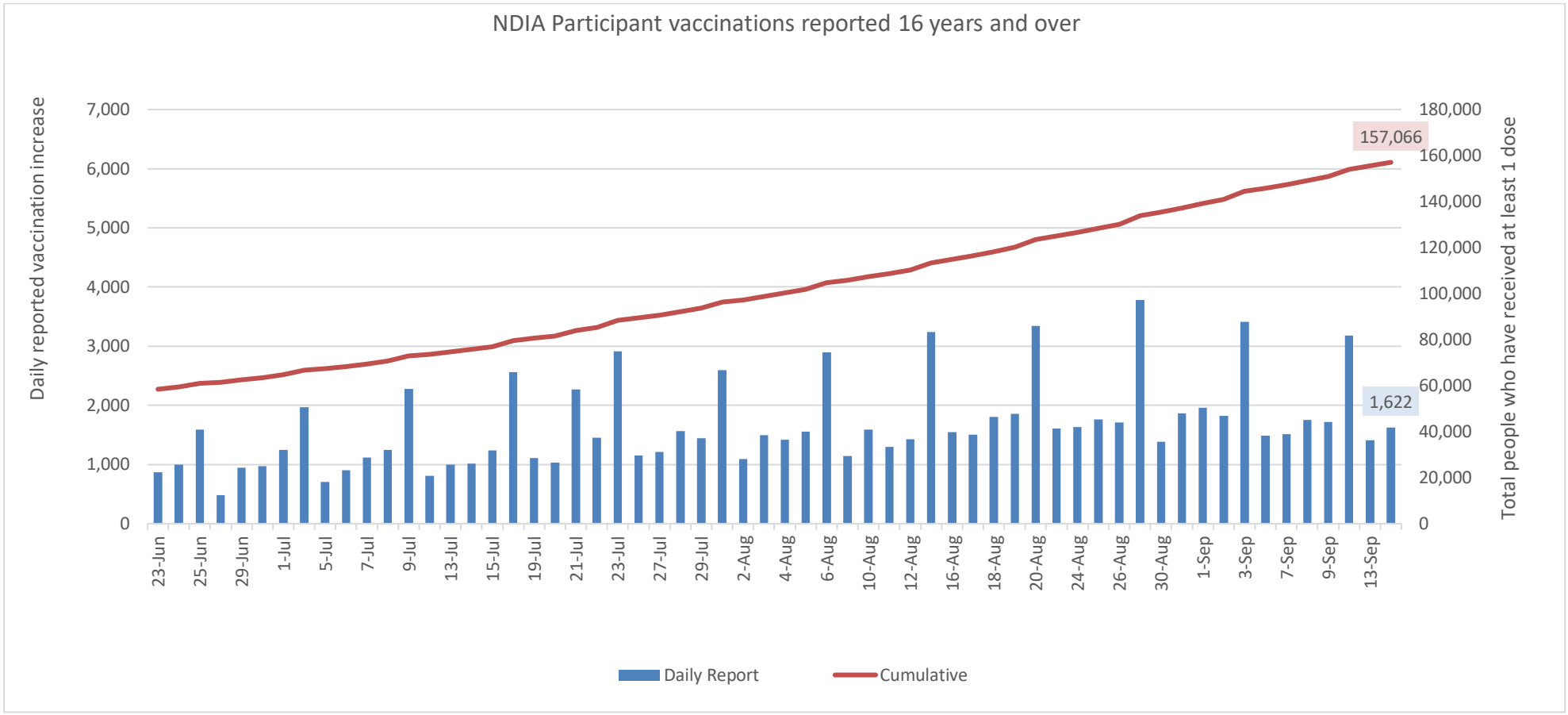

Figure 1: NDIS Participant reported vaccination trend (Aged 16 and over)

Table 2: Total vaccines reported for NDIS participants by dose and state or territory

Jurisdiction	Total NDIS participants that have received 1 dose	Total NDIS participants that have received dose 2	Total people who have received at least one dose	**Total Doses**	Total NDIS participants aged 12-15	Percentage who have received at least one dose	Percentage who have received 2 doses	Change in total people who have received at least one dose since last report	% Change in total people who have received at least one dose since last report	% Change in total people who have received two doses since last report
NSW	2,104	294	2,398	2,692	14,368	16.7%	2.0%	+191	+8.7%	+10.1%
VIC	1,843	145	1,988	2,133	11,592	17.1%	1.3%	+142	+7.7%	+14.2%
QLD	604	155	759	914	9,827	7.7%	1.6%	+39	+5.4%	+4.7%
WA	213	31	244	275	4,708	5.2%	0.7%	+28	+13.0%	+6.9%
SA	213	26	239	265	5,474	4.4%	0.5%	+31	+14.9%	+8.3%
TAS	72	6	78	84	1,064	7.3%	0.6%	+8	+11.4%	+0.0%
ACT	111	18	129	147	879	14.7%	2.0%	+18	+16.2%	+12.5%
NT	70	3	73	76	396	18.4%	0.8%	+2	+2.8%	+50.0%
National	**5,230**	**678**	**5,908**	**6,586**	**48,308**	**12.2%**	**1.4%**	**+459**	**+8.4%**	**+9.5%**

Note: Total NDIA participant numbers obtained as of 30 June, 2021 (aged 12-15 years).

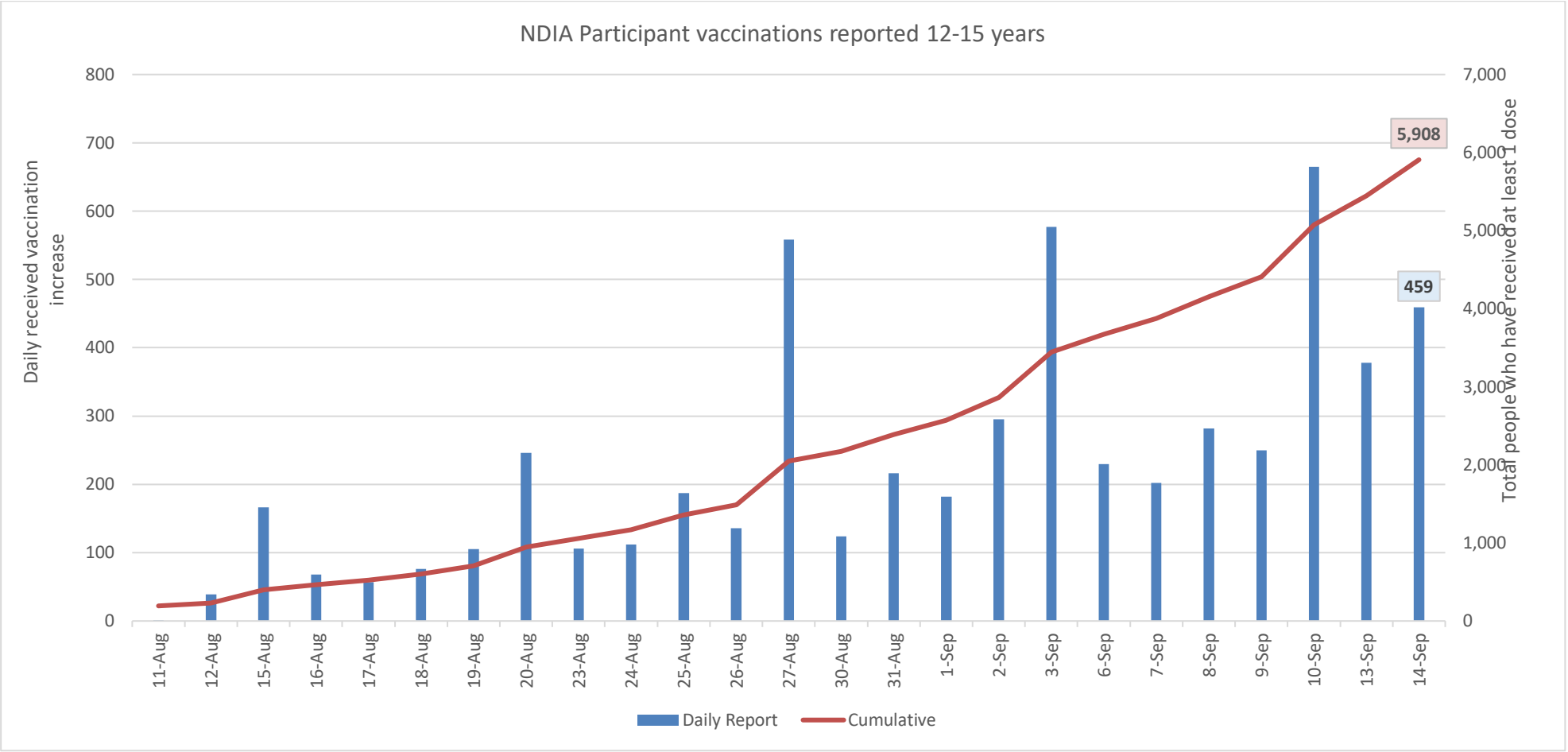

Figure 2: NDIS Participant reported vaccination trend (aged 12-15 years old)

Table 3: Total vaccines reported for NDIS Participants in residential settings by dose

	Total NDIS participants that have received 1 dose	Total NDIS participants that have received dose 2	Total people who have received at least one dose	**Total doses**	*Total NDIS participants aged 16 and over in these settings*	Percentage who have received at least one dose	Percentage who have received 2 doses	Change in people who have received at least one dose since last report	% Change in people who have received at least one dose since last report
NDIS participants living in disability accommodation*	2,380	13,621	**16,001**	**29,622**	22,368	71.5%	60.9%	+55	+0.3%
NDIS participants living in residential aged care	331	3,631	**3,962**	**7,593**	4,925	80.4%	73.7%	+1	+0.0%
NDIS participants in congregate accommodation settings (disability + aged care)	2,711	17,252	**19,963**	**37,215**	27,293	73.1%	63.2%	+56	+0.3%

* Disability accommodation means two or more people with disability living in shared residential accommodation, as per the eligibility criteria of Phase 1a.

**25 vaccinated participants have been identified with both Supported Independent Living (SIL) and Residential Aged Care indicators. Duplicates have been removed from total calculation.

Table 4: Total vaccines reported for NDIS participants living in disability accommodation*

NDIS Participants living in disability accommodation						
Jurisdiction	Total NDIS participants that have received 1 dose	Total NDIS participants that have received dose 2	Total people who have received at least one dose	Total Doses	Total NDIS participants aged 16+ and over	Percentage who have received at least one dose
NSW	1,155	4,943	6,098	11,041	8,198	74.4%
VIC	303	3,444	3,747	7,191	4,746	79.0%
QLD	529	1,813	2,342	4,155	3,918	59.8%
WA	110	1,195	1,305	2,500	1,892	69.0%
SA	169	1,228	1,397	2,625	2,023	69.1%
TAS	62	510	572	1,082	802	71.3%
ACT	22	318	340	658	447	76.1%
NT	30	170	200	370	342	58.5%
National	**2,380**	**13,621**	**16,001**	**29,622**	**22,368**	**71.5%**

* Disability accommodation means two or more people with disability living in shared residential accommodation, as per the eligibility criteria of Phase 1a.

Table 5: Total vaccines reported for NDIS participants living in residential aged care

NDIS Participants living in residential aged care						
Jurisdiction	Total NDIS participants that have received 1 dose	Total NDIS participants that have received dose 2	Total people who have received at least one dose	Total Doses	Total NDIS participants aged 16+ and over	Percentage who have received at least one dose
NSW	135	1,261	1,396	2,657	1,719	81.2%
VIC	60	1,080	1,140	2,220	1,396	81.7%
QLD	77	653	730	1,383	941	77.6%
WA	20	275	295	570	364	81.0%
SA	29	214	243	457	310	78.4%
TAS	3	83	86	169	108	79.6%
ACT	4	34	38	72	40	95.0%
NT	3	31	34	65	47	72.3%
National	**331**	**3,631**	**3,962**	**7,593**	**4,925**	**80.4%**

Notes:

- Data matching between the NDIA and AIR is limited as there is no unique common identifier between data sources.
- Participant data sources have been matched on the following criteria:
  - Last name
  - Date of birth
  - At least one of first name or postcode
- The lack of unique identifies can lead to false matches, omissions or other errors. This means that the data above is subject to a margin of error, which should be taken into consideration when interpreting results. It is recommended that published results be rounded to the nearest 100.
- Further work is being undertaken to apply a probabilistic record linkage approach to future reports which will aid in delivering a confidence weighting to results.

United Kingdom

OpenSafely data platform reports[2]

The following data is sourced from OpenSAFELY (a new secure analytics platform for electronic patient records built on behalf of NHS England to deliver urgent academic and operational research during the pandemic).This data captures COVID-19 vaccination coverage in England using data from 40% of general practices that use TPP electronic health record software.

Data code definitions

Learning disability:

- Complete trisomy 13 syndrome
- Complete trisomy 18 syndrome
- Complete trisomy 21 syndrome
- Distal trisomy 18q
- Intellectual disability
- Mild learning disability
- Moderate learning disability
- On learning disability register
- Partial trisomy 13 in Patau's syndrome
- Partial trisomy 18 in Edward's syndrome
- Partial trisomy 21 in Down's syndrome
- Profound learning disability
- Severe learning disability
- Significant learning disability
- Specific learning disability
- X-linked epilepsy with learning disability and behaviour disorder syndrome

Shielding: Highest risk category (clinically extremely vulnerable) for developing complication from coronavirus disease 19 caused by COVID-19 who were asked to 'shield.' Note: the data below differentiates patients who were on the shielded patient list; however, the shielding program has recently ended and it is thought unlikely that people will be asked to shield again.[3,4]

Care home: Lives in a residential home, hospice or staffed home

Table 6: Overview of Vaccination Figures to date for patients of practices that use TPP electronic health record software in England

	First dose as at 06 Oct 2021	Second dose as at 06 Oct 2021	Third dose as at 06 Oct 2021
Total vaccinated in TPP	16,239,202	15,138,809	617,064
80+	96.4% (1,040,172 of 1,078,826)	95.3% (1,027,635 of 1,078,826)	22.4% (242,144 of 1,078,826)
70-79	96.0% (1,979,264 of 2,062,592)	95.0% (1,958,957 of 2,062,592)	5.0% (102,872 of 2,062,592)
care home	95.6% (84,161 of 87,990)	92.4% (81,312 of 87,990)	7.3% (6,433 of 87,990)
shielding (aged 16-69)	90.9% (763,945 of 840,665)	87.6% (736,806 of 840,665)	3.9% (32,676 of 840,665)
65-69	93.5% (1,005,074 of 1,075,053)	92.3% (992,509 of 1,075,053)	1.8% (19,810 of 1,075,053)
LD (aged 16-64)	87.2% (73,094 of 83,811)	82.3% (68,992 of 83,811)	0.5% (420 of 83,811)
60-64	91.8% (1,177,295 of 1,282,610)	90.3% (1,157,961 of 1,282,610)	2.7% (35,056 of 1,282,610)
55-59	90.0% (1,367,506 of 1,519,784)	88.1% (1,338,750 of 1,519,784)	2.9% (44,296 of 1,519,784)
50-54	87.7% (1,380,071 of 1,573,068)	85.3% (1,342,579 of 1,573,068)	2.7% (41,699 of 1,573,068)
40-49	80.3% (2,388,043 of 2,974,342)	76.4% (2,271,367 of 2,974,342)	1.5% (44,737 of 2,974,342)
30-39	69.9% (2,342,466 of 3,352,118)	63.3% (2,120,601 of 3,352,118)	0.9% (29,484 of 3,352,118)
18-29	66.8% (2,339,582 of 3,503,157)	56.1% (1,964,151 of 3,503,157)	0.5% (17,255 of 3,503,157)
16-17	56.8% (298,543 of 525,819)	14.7% (77,189 of 525,819)	0.0% (196 of 525,819)

Table 7: Cumulative vaccination figures among shielding (aged 16-69) population

		Vaccinated at 06 Oct (n)	Vaccinated at 06 Oct (%)	Total eligible	Previous week's vaccination coverage (%)	Vaccinated over last 7d (%)
overall	**overall**	763942	90.9	840665	90.8	0.1
newly shielded since feb 15	**no**	463099	93.0	497861	93.0	0.0
	yes	300839	87.8	342804	87.7	0.1
Sex	**F**	428316	90.6	472528	90.6	0.0
	M	335615	91.2	368123	91.1	0.1
Age band	**16-29**	58030	82.2	70574	82.1	0.1
	30-39	109417	85.1	128541	85.0	0.1
	40-49	150997	89.9	168042	89.8	0.1
	50-59	215621	92.9	232120	92.9	0.0
	60-69	229866	95.2	241374	95.2	0.0
Ethnicity (broad categories)	**Black**	34279	76.5	44835	76.3	0.2
	Mixed	11578	80.3	14427	80.1	0.2
	Other	15064	82.1	18340	82.0	0.1
	South Asian	96313	88.7	108633	88.5	0.2
	Unknown	25375	88.5	28679	88.5	0.0
	White	581322	92.9	625737	92.9	0.0
Index of Multiple Deprivation (quintiles)	**1 Most deprived**	214459	87.4	245462	87.3	0.1
	2	170464	90.1	189168	90.0	0.1
	3	147476	92.1	160125	92.0	0.1
	4	118174	93.8	126021	93.7	0.1
	5 Least deprived	93702	95.4	98266	95.3	0.1
	Unknown	19656	91.0	21602	90.9	0.1
Learning disability	**no**	738633	90.8	813617	90.7	0.1
	yes	25298	93.6	27034	93.6	0.0

Table 8: Cumulative vaccination figures among Learning Disabilities (aged 16-64) population (excluding those who are shielding)

		Vaccinated at 06 Oct (n)	Vaccinated at 06 Oct (%)	Total eligible	Previous week's vaccination coverage (%)	Vaccinated over last 7d (%)
overall	**overall**	73095	87.2	83811	87.1	0.1
Sex	**F**	28252	89.2	31675	89.1	0.1
	M	44835	86.0	52136	85.9	0.1
Age band	**16-17**	3591	74.5	4823	74.2	0.3
	18-29	25375	83.6	30345	83.5	0.1
	30-34	9303	86.4	10773	86.4	0.0
	35-39	6951	88.9	7819	88.8	0.1
	40-44	5586	91.1	6132	91.0	0.1
	45-49	5684	92.2	6167	92.1	0.1
	50-54	6097	93.3	6538	93.3	0.0
	55-59	5999	93.3	6433	93.3	0.0
	60-64	4515	94.4	4781	94.3	0.1
Ethnicity (broad categories)	**Black**	889	64.1	1386	64.1	0.0
	Mixed	812	73.0	1113	73.0	0.0
	Other	553	76.0	728	75.0	1.0
	South Asian	3794	78.9	4809	78.6	0.3
	Unknown	5250	85.8	6118	85.7	0.1
	White	61796	88.7	69657	88.7	0.0

Table 9: Cumulative vaccination figures for older adults with learning disabilities (excluding those who are shielding)

AGE GROUP	DISABILITY	Vaccinated at 06 Oct (n)	Vaccinated at 06 Oct (%)	Total eligible	Previous week's vaccination coverage (%)	Vaccinated over last 7d (%)
80+	No Learning disability	1039675	96.4	1078308	96.4	0.0
	Learning disability	490	94.6	518	94.6	0.0
70-79	No Learning disability	1976429	96.0	2059624	95.9	0.1
	Learning disability	2821	95.5	2954	95.5	0.0
65-69	No Learning disability	1002743	93.5	1072540	93.5	0.0
	Learning disability	2324	92.7	2506	92.7	0.0

Table 10: Cumulative vaccination figures for adults (aged 50+) with psychosis, schizophrenia, or bipolar (excluding those who are shielding)

AGE GROUP	DISABILITY	Vaccinated at 06 Oct (n)	Vaccinated at 06 Oct (%)	Total eligible	Previous week's vaccination coverage (%)	Vaccinated over last 7d (%)
80+	Without condition	1032381	96.4	1070510	96.4	0.0
	Psychosis, schizophrenia, or bipolar	7784	93.6	8316	93.5	0.1
70-79	Without condition	1960413	96.0	2042229	96.0	0.0
	Psychosis, schizophrenia, or bipolar	18837	92.6	20349	92.5	0.1
65-69	Without condition	994616	93.5	1063363	93.5	0.0
	Psychosis, schizophrenia, or bipolar	10451	89.5	11676	89.5	0.0
60-64	Without condition	1164373	91.8	1267728	91.8	0.0
	Psychosis, schizophrenia, or bipolar	12922	86.9	14875	86.8	0.1
55-59	Without condition	1351329	90.0	1500758	90.0	0.0
	Psychosis, schizophrenia, or bipolar	16163	85.0	19019	84.9	0.1
50-54	Without condition	1363565	87.8	1553034	87.8	0.0
	Psychosis, schizophrenia, or bipolar	16492	82.4	20020	82.3	0.1

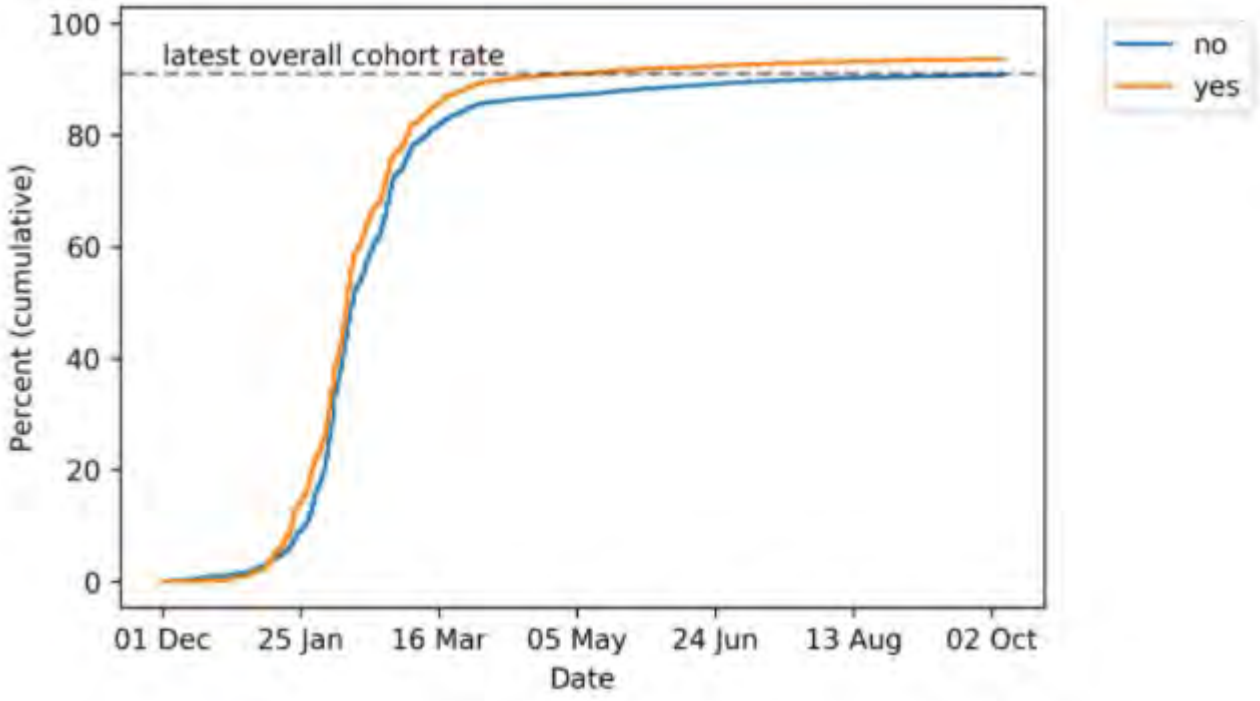

Figure 3: COVID-19 vaccinations among shielding population with learning disability (aged 16-69)

Table 11: Cumulative vaccination figures among care home population (includes those known to live in an elderly care home)

		Vaccinated at 06 Oct (n)	Vaccinated at 06 Oct (%)	Total eligible	Previous week's vaccination coverage (%)	Vaccinated over last 7d (%)
Category	**Group**					
overall	**overall**	84162	95.6	87990	95.5	0.1
Sex	**F**	59801	95.9	62363	95.8	0.1
	M	24360	95.1	25627	94.9	0.2
Age band	**65-69**	4725	94.0	5026	94.0	0.0
	70-74	7406	94.3	7854	94.2	0.1
	75-79	10248	95.3	10759	95.2	0.1
	80-84	15323	95.8	15995	95.7	0.1
	85-89	19964	95.8	20846	95.6	0.2
	90+	26502	96.3	27517	96.2	0.1
Ethnicity (broad categories)	**Black**	441	85.1	518	83.8	1.3
	Mixed	238	94.4	252	91.7	2.7

		Vaccinated at 06 Oct (n)	Vaccinated at 06 Oct (%)	Total eligible	Previous week's vaccination coverage (%)	Vaccinated over last 7d (%)
Category	**Group**					
	Other	364	94.5	385	94.5	0.0
	South Asian	630	92.8	679	91.8	1.0
	Unknown	1806	92.1	1960	92.1	0.0
	White	80689	95.8	84196	95.7	0.1
Dementia	**no**	37590	94.6	39746	94.5	0.1
	yes	46571	96.5	48244	96.4	0.1

Canada

Vaccine coverage in Ontario, Canada[5]

Table 12: COVID-19 Vaccine Coverage by Priority Group, among individuals living outside of long-term care facilities, as of September 12, 2021

	12-64 years			65+ years		
	Total number of individuals 12-64 years with the condition	**Percentage with at least 1 vaccine dose**	**Percentage with both vaccine doses**	**Total number of individuals 65+ years with the condition**	**Percentage with at least 1 vaccine dose**	**Percentage with both vaccine doses**
Individuals with any highest-risk condition	90,415	68%	60%	16,293	91%	88%
History of solid organ transplants	11,935	85%	81%	7,140	89%	87%
History of hematopoetic stem cell transplant	4,933	82%	78%	2,952	89%	86%
Neurological diseases in which respiratory function may be compromised	415	73%	67%	522	72%	64%
Hematological malignancy diagnosed < 1 year ago	88	80%	74%	135	86%	84%
Chronic kidney disease (with recent receipt of dialysis)	5,044	88%	84%	6,883	94%	92%
Pregnancy	70,221	64%	54%	N/A	N/A	N/A
Individuals with any high-risk condition	148,983	79%	72%	118,043	95%	93%
Other treatment causing immunosuppression	33,597	83%	77%	111,416	95%	93%
Intellectual or developmental disability	116,251	77%	70%	6,862	89%	86%
Among adults (18+) with intellectual or developmental disability	87,750	79%	72%	6,862	89%	86%
Individuals with any at-risk condition	3,022,183	80%	74%	1,694,437	89%	86%
Immune deficiencies/Autoimmune diseases	292,498	84%	79%	172,279	91%	89%
Stroke/cerebrovascular disease	39,698	82%	78%	122,637	87%	84%
Dementia	8,559	86%	82%	104,120	85%	81%
Diabetes	704,935	86%	81%	808,875	88%	86%
Liver disease	44,512	81%	75%	38,042	86%	82%
Chronic kidney disease	97,725	84%	79%	217,857	89%	85%
All other cancers	115,635	83%	79%	144,886	90%	87%
Respiratory diseases	1,931,527	79%	72%	729,182	89%	86%
Heart disease	181,787	84%	80%	489,041	88%	86%
Severe mental illness	54,765	71%	61%	5,641	85%	80%
Substance use disorder	93,271	59%	46%	5,142	86%	79%
Thalassemias	6,635	81%	74%	1,900	85%	82%
Other immunocompromising health conditions	81,197	79%	73%	35,125	87%	84%
Individuals with any risk condition (highest-risk/high-risk/at-risk)	3,149,840	80%	74%	1,711,922	89%	86%
Individuals with none of the listed conditions	7,272,905	77%	71%	1,022,958	85%	83%
Recent experience with homelessness	15,155	52%	36%	1,188	71%	60%

References

1 Data sourced from Department of Social Services - Disability and Carers Stream. (5 October 2021).

2 *OpenSafely Vaccine Coverage - UK*, <https://reports.opensafely.org/reports/vaccine-coverage/#charts40> (04 Oct 2021).

3 *Coronavirus guidance for high-risk groups*, <https://www.asthma.org.uk/advice/triggers/coronavirus-covid-19/shielding-advice-high-risk/> (2021).

4 *Guidance for people previously considered clinically extremely vulnerable from COVID-19*, <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19> (2021).

5 *ICES COVID-19 Dashboard*, <https://www.ices.on.ca/DAS/AHRQ/COVID-19-Dashboard> (October 8, 2021).

Supporting people with a learning disability and autistic people to get the COVID-19 vaccination

Top tips for volunteers

As a volunteer, you may be the first person somebody arriving for their vaccination will meet, so be mindful that the environment and the personal protective equipment you are wearing may cause the person stress and anxiety.

Smile, even if you have a face mask on, as this will still come through to the person.

Use plain English, avoid use of jargon, speak slowly and clearly, be calm as well as patient.

Please don't assume that someone is unable to communicate. Check with the person and/or their carer.

Remember to ask what would help the person and be as flexible, understanding and as accommodating as possible.

Remember!

Talk to the person in a kind and friendly way. Be patient and help them to feel in control.

Top tips:

- ✓ **The person may need someone to accompany them so they know where to go**
- ✓ **Where possible let the person know approximately how long they may have to wait**
- ✓ **The person may prefer to wait in their car and be called in or texted, only when the team are ready to give them their vaccination**
- ✓ **The person may prefer having their vaccination in their car, if possible**
- ✓ **Provide a less brightly lit space where possible**
- ✓ **If you are asked a question and you don't know the answer, please don't be afraid to admit this and say you will find out from someone who does**

Further resources

NHS reasonable adjustment guide for staff supporting people with a learning disability, autism or both
https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/

NHS England and NHS improvement advice on using the right words

Autism fact sheets (short resource developed for NHS volunteer responders)

Learning disability fact sheets (short resource developed for NHS volunteer responders)

PHE vaccination leaflet easy-read https://www.gov.uk/government/publications/covid-19-vaccination-easy-read-resources.

Guidance on Mental Capacity Act
https://www.gov.uk/government/publications/coronavirus-covid-19-looking-after-people-who-lack-mental-capacity/the-mental-capacity-act-2005-mca-and-deprivation-of-liberty-safeguards-dols-during-the-coronavirus-covid-19-pandemic-additional-guidancea#best-interest-decisions

MENCAP Treat me Well Campaign (https://www.mencap.org.uk/get-involved/campaign-mencap/treat-me-well).

MENCAP Equality Act easy read PDF
https://www.mencap.org.uk/sites/default/files/2018-02/Equality%20Act%20-%20Easy%20Read.pdf.

NICE clinical guide for frontline staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic
https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/learning-disability-autism-during-pandemic.pdf.

Supporting people with a learning disability and autistic people to get the COVID-19 vaccination

Top tips for primary care teams

In keeping with the Equality Act 2010, we need to provide reasonable adjustments to disabled people. Providing appropriate reasonable adjustments can make the difference between a person with a learning disability, autism or both having the vaccine or not.

This means taking away any barriers or providing extra support, so it's easier for an individual to feel safe and comfortable when receiving their vaccine.

A good experience at a person's first appointment will help ensure they feel comfortable and confident when returning for their second appointment. Be mindful that the environment and the personal protective equipment you are wearing may cause the person stress and anxiety.

This guide contains top tips to best support a person who is autistic, who has a learning disability or both. These considerations may also be useful when supporting other disabled people.

Remember!

Every person has their own needs and concerns. Be patient. Help the person feel in control. Make sure you are thinking about what each person needs before, during and after the appointment to ensure that vaccinations will be more efficient and successful.

Before and during the appointment

- Make sure people are told about their appointment as early as possible, in an accessible way they can understand.
- Ask the person if they want you to send them a text or email with their appointment date, time and place and if possible, a link to what the location looks like.
- Confirm with them/their carer that they can take someone with them to the appointment if they want to.
- Ask the person and their carer about any concerns they may have, including what they might find stressful and what reasonable adjustments could help with this. **See page 2 for some examples.**
- Where the use of face masks may cause distress or inhibit communication and understanding, consider alternative options and carry out a risk assessment.

You can use the easy-read vaccination guide to help explain to the person what the vaccination involves:
https://www.gov.uk/government/publications/covid-19-vaccination-easy-read-resources.

After the appointment

If it is the person's first vaccination, make sure they are aware they will need to have another one. Make sure they understand why. Check their understanding.

Make sure the person has a copy of their vaccination record card, that it is filled in, and that they know to keep it safe.

It might help to give the person the 'What to expect after vaccination' leaflet, also available in easy read if they need it: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/963183/Easy_Read_what_to_expect_after_your_vaccination_leaflet.pdf.

Some examples of reasonable adjustments

This list is not exhaustive:

- Check the person's summary care record for any specific needs
- Where possible, hold the appointment in a local and familiar place
- Offer to give the vaccine at home or in their car/cab, if possible
- Provide a quiet or less brightly lit space
- Schedule appointment times at the quietest times of the day
- Provide double appointment times so you are not rushed
- Check if the person is scared of needles. Find out what may help them
- The option of waiting in a quiet room, if one is available
- The option of waiting in their car outside and being texted or called on their mobile when ready
- Using plain English and no medical jargon
- Having easy read and accessible resources, materials and information to hand
- Check they have fully understood what you have told them by asking them and their carer
- Send a reminder before the appointment by calling or texting
- Talk to the person in a kind and friendly way throughout their appointment to ease anxiety
- Check what might help to distract the person or to help keep them calm

If someone isn't sure what would help them, but appears to be distressed, it is okay to make some suggestions and let them decide what might be helpful – but don't overwhelm them with too many options. Keep it simple.

Further resources

NHS reasonable adjustment guide for staff supporting people with a learning disability, autism or both https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/

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MENCAP Equality Act easy read PDF https://www.mencap.org.uk/sites/default/files/2018-02/Equality%20Act%20-%20Easy%20Read.pdf.

NICE clinical guide for frontline staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/learning-disability-autism-during-pandemic.pdf.