



Lessons learned during the COVID-19 pandemic

Advisory Committee on the Health Emergency Response to COVID-19
for People with Disability

February 2023

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Executive Summary

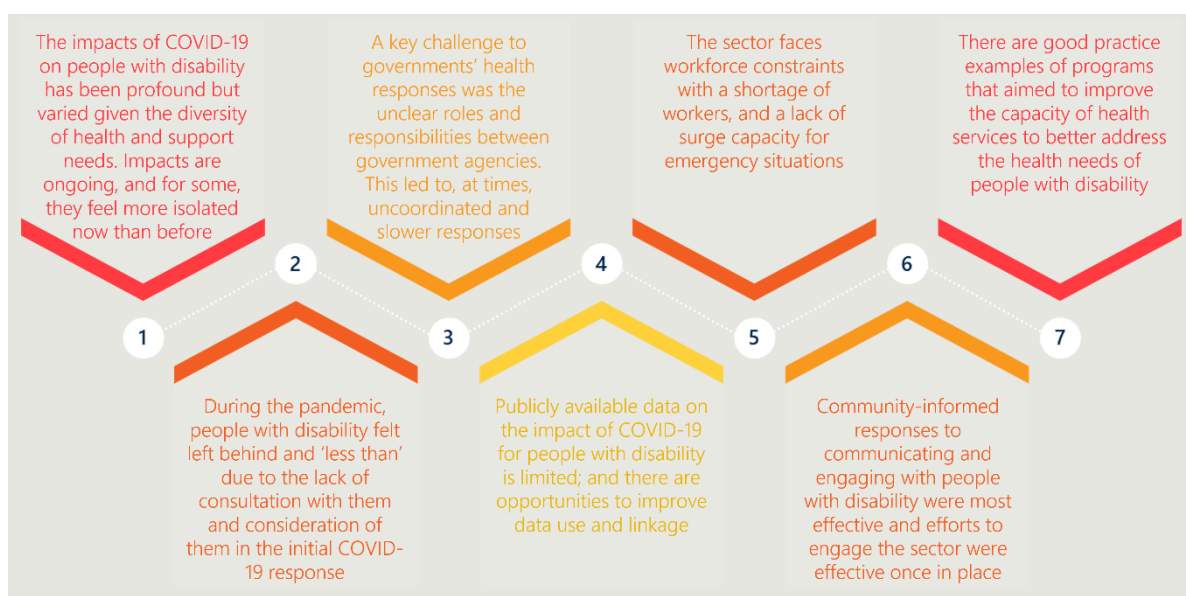
The Department of Health and Aged Care (the Department) has engaged Nous Group (Nous) to develop a report that records the lessons learned by the Advisory Committee on the Health Emergency Response to COVID-19 for People with Disability (the Committee) over the course of the COVID-19 pandemic. The report covers:

- key learnings of the Committee, and views from those with lived experience of disability, over the course of the COVID-19 pandemic
- recommendations that suggest how those learnings can contribute to future health emergency preparedness and response.

To develop the report, Nous conducted interviews with and received written submissions from Committee members (including select Commonwealth agencies), and state and territory government representatives who are invited to Committee meetings. Focus groups and interviews were also held with people with disability, their families and carers, and workers. The report presents key learnings that reflect the views of those engaged, collectively referred to as 'stakeholders' (see Figure 1).

Information from broader sources including hearing reports produced by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability were only used to provide context to insights provided by stakeholders.

Figure 1 | High-level synthesis of key learnings of Committee members, state and territory representatives and people with lived experience of disability



Recommendations, informed by the key learnings of the Committee, have also been developed for the Australian Government, Australian Department of Health and Aged Care, Australian Department of Social Services, National Disability Insurance Agency (NDIA), NDIS Quality and Safeguards Commission and state and territory governments to consider. These aim to provide practical advice on how government agencies could improve responses to COVID-19 and future health emergencies for people with disability.

Section 1 of the report provides an overview of the project; and the key learnings of the Committee are summarised at a high level as headings under each of the sections below.

- Section 2: stakeholder views of the impact of COVID-19 for people with disability
- Section 3: stakeholder views of the health system responses
- Section 4: stakeholder views of the health service and program responses
- Section 5: stakeholder views of the role of sectors outside of health
- Section 6: stakeholder views of the preparedness and responses of workforces.

1 Project overview

The Department of Health and Aged Care (the Department) has engaged Nous to conduct a report of lessons learned by the Committee during the COVID-19 pandemic. Established in April 2020, the Committee:

- provides expert advice on the health care needs of people with disability, their families and carers, and the disability service sector.
- oversees the development and implementation of the Management and Operational Plan for People with Disability (the Plan).¹

The Plan provides high-level guidance on considerations in the management and prevention of COVID-19 for people with disability. It includes a commitment to review and learn from the COVID-19 pandemic response for people with disability.²

To support this objective, the Department engaged Nous to develop an independent report that records the lessons learned by the Committee, and a selection of people with lived experience of disability, over the course of the COVID-19 pandemic and provide recommendations informed by them. The report covers:

- key learnings of the Committee over the course of the COVID-19 pandemic
- recommendations that suggest how those learnings can contribute to future health emergency preparedness and response.

IN THIS DOCUMENT

- **Disability** is recognised as ‘an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.’³
- **Carer** refers to a person who provides unpaid care and support to family members and friends who have a disability.
- **Support worker** refers to anyone who is employed or otherwise engaged to provide disability supports and services to people with disability.
- The term **worker** is used to refer to people across a diverse range of occupation groups who are employed or otherwise engaged to provide health care and/or disability supports to people with disability. This includes people from a broad range of occupation groups, such as allied health professionals and disability support workers.

1.1 Method and approach

Nous conducted interviews with and received written submissions from Committee members (including select Commonwealth agencies), and state and territory representatives. Focus groups and interviews were also held with people with disability, their families and carers, and workers. Collectively, Committee members, state and territory representatives and people with lived experience who attended focus groups and interviews will be referred to as ‘stakeholders’.

Nous also conducted a literature review of available reports and research into the impact of COVID-19 for people with disability, their families and carers, and workers. This supporting information was used to provide context to information provided by the Committee, and others engaged including state and territory government representatives and people with lived experience. It included a review of publicly available submissions to, and hearing reports produced by, the Royal Commission into Violence, Abuse,

² Australian Government Department of Health and Aged Care, Management and Operational Plan for People with Disability, December 2021.

³ UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, preamble.

Neglect and Exploitation of people with disability (the Royal Commission) regarding impacts of COVID-19 on people with disability, which stakeholders often referred to. Figure 2 summarises the number of interviews, submissions and focus groups held to inform this report. A full list of organisations that contributed can be found in Appendix A.

Figure 2 | Scale of input to inform this report



The recommendations in this report synthesise perspectives gathered through the consultations and are informed by key learnings of the Committee. As a result, the recommendations should be read as the recommendations of the Committee.

2 Stakeholder views of the impact of COVID-19 for people with disability

The following sections summarise what we heard from Committee members, and people with lived experience of disability, about the experiences of people with disability, their families and carers, and workers during the COVID-19 pandemic. Despite having unique experiences with COVID-19, those consulted unanimously stated that the impact has been and continues to be profound.

Summary of key learnings:

Committee members, state and territory representatives and those with lived experience engaged through the process shared the following lessons learned about the impacts of COVID-19 for people with disability:

- People with disability are a diverse group and every COVID-19 experience has been different
- For many people with disability, the impact of COVID-19 has been far more significant than for people without disability
- People with disability are at higher risk of COVID-19 infection and adverse outcomes
- Vaccination rates for certain people with disability remain low
- The impacts of COVID-19 and the associated physical isolation for people with disability are ongoing
- Improved data availability and linkage will enable a better understanding of the whole-of-life or longer-term impacts of COVID-19 for people with disability.

2.1 People with disability are a diverse group and every COVID-19 experience has been different

People with lived experience of disability, and several Committee members emphasised that people with disability are a broad and diverse group with varied health and support needs. Therefore, the impact of COVID-19 has been profound, yet different for each of the 4.4 million Australians with disability.⁴ The level of vulnerability of a person with disability can depend on the complex interactions between the person's disability support needs, health, social and socio-economic factors.

People with disability often face numerous inequities to accessing health care and other necessary services, which Committee members stated existed long before the COVID-19 pandemic. Members, and people with lived experience, similarly argued that the COVID-19 pandemic highlighted and, in many ways, deepened these inequities.

"COVID-19 has had a profound impact on people with disability. But that impact is not equal for everyone. People with disability are a diverse group and even within specific types of disabilities there is great variance between people who have the same condition."

— Committee member

⁴ The Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings, 2018.

"COVID-19 has magnified existing inequalities particularly: increased isolation (shielding), increased uncertainty and fear (of worsened COVID-19 health outcomes, disruption to usual health and wellbeing supports) [and] low level of public trust (preferred information sources being peers and peak organisations)."

— State/territory government representative

2.2 For many people with disability, the impact of COVID-19 has been far more significant than for people without disability

Despite the lifting of restrictions, COVID-19 remains prevalent in communities across Australia and continues to impact people with disability. Committee members and people with lived experience stated that the pandemic and its impact on people with disability is still very much ongoing. In engagements with Committee members, state and territory government representatives and people with lived experience, the COVID-19 pandemic was generally broken down into three stages:

- pre vaccination stage
- post vaccination stage
- the current, ongoing endemic stage.

2.2.1 Pre vaccination stage

During the pre-vaccination stage of COVID-19, people with lived experience noted that they went into self-isolation and a 'lockdown' equivalent situation much sooner than people without disability. Committee members and people with lived experience reported that those with children with a disability removed them from school at an earlier time than others due to the fear of contracting COVID-19. Other carers and people with disability discussed loss of their essential services and the difficult decisions they had to make about what in-person services to continue if they were available. This left them feeling isolated.

"[We] were told early on that if my child caught COVID she might not survive so we chose to self-isolate as a family. It was tricky for all my children missing school and most of my friends did not understand why we isolated so much longer."

— Person who cares for someone with a disability

Some Committee members recounted how it took time for people with intellectual disability to understand COVID-19 and government responses to it, including why they could not go outside safely or see their friends and family. Additionally, Committee members noted that for some people with certain disabilities, facemasks made it difficult for them to interact with others because they depend on being able to read lips and facial expressions.

During COVID-19 lockdown mandates, several carers interviewed explained how the lockdowns were not conducive to the care arrangements in place for people with disability. They noted that the cost of workers increased. It was also noted that the supply of experienced workers and the quality of care received decreased. Other carers discussed that they needed to breach travel guidelines to transit further than was allowed to continue their caregiver duties.

Despite this, there were reports of resilience and innovation among people with disability, their families and carers, and workers. People with lived experience interviewed shared stories of using video conferencing to maintain social interactions, creating their own coffee shop in their supported accommodation service, and pursuing a first-aid certification.

I have a lot of new anxiety since COVID-19 began. There was a lot of fear mongering on TV. I cannot see what 1.5 metres is and my guide dog isn't trained in 1.5 metres. I tried to get out for walks, but **people would come and brush past me and touch me**. To help me navigate, I have to touch so many surfaces. If I am getting into a lift, I have to feel along the wall to get the buttons. My fear and anxiety of going out was heightened because I had no control over that, and **I could not see if people were wearing masks**.

I hired a disability support worker to take me to and from work to make sure I avoided cabs. **I later found out that she was not wearing a mask and taking advantage of the fact that I could not see**. My interaction with the one support worker **made me lose trust in everyone else**. I had a house cleaner who I would not let come in and I discontinued use of a lot of services. **I can get away with not using support workers, but it really impacts my independence**.

2.2.2 Post vaccination stage

Some Committee members and people with lived experience described the decisions they had to make post-vaccination regarding how much of their 'normal' life they should resume. For example, one Committee member noted that as lockdown ended, and in-person school and services resumed, they still had to choose how much risk they wished to take on and whether their child with disability should return to in-person schooling.

Committee members and carers with young children mentioned they had to determine how they could send their children back to school safely, especially when children generally had lower vaccination rates. One Committee member discussed how they had to advocate for their child's school to put in place COVID-19 safety plans. For example, it was reported to not be standard practice for the school to use any personal protective equipment (PPE) when providing support to children with disability who are at high risk of adverse health outcomes from COVID-19. Other carers also reported having to advocate for plans and policies to try to mitigate risks to their child's safety at school.

"When my child re-entered school there was no thought about how to put kids who are medically complex back into a school site. I worked up an individualised risk management plan because my child does not understand things like hand hygiene and requires support with activities like going to the bathroom."

— Committee member

Committee members and carers who were interviewed also noted there was increased stress placed on carers due to the lack of supports provided to them from the start of the pandemic. They noted that post-vaccination they have felt a great burden of responsibility in deciding what activities to resume and what risks to take as COVID-19 still presents risk for people with disability. This is compounded with loss of support and in-person services that has resulted in increased responsibility for carers. They noted this placed ongoing and increased stress on them.

A few Committee members noted that for some people with disability, planned medical care and procedures were put off due to COVID-19 restrictions. They noted that medical procedures for non-COVID-19 health conditions had been delayed or missed as a result. It was also reported that as normal

"The waiting lists are crazy right now; people are needing more treatment now than they did before. Behaviour went backwards. People with physical disabilities have experienced lost muscle tone because they were not able to do their activities."

— Committee member

life resumed, and in-person services became more widely available again there has been a long queue in some situations for certain services. Other Committee members discussed the loss of progress for people with disability who experienced discontinuation of their services.

LIVED EXPERIENCE STORY | CARER OF CHILD WITH DISABILITY

There is a lot of medical stuff that has come along with the disability. **Right when COVID began, we started self-isolating long before the lockdown because my child was so high risk.** Caring for all my children is very challenging. My one child is trying to escape and jump off things. My two children with ASD have frequent meltdowns. I did not have NDIS for one of my children in the beginning. **I really struggled and I ended up having a semi-breakdown myself.**

Since then, they have had the vaccinations. I really wish they would have done something about that sooner. This really infuriated me. **Everyone was so blasé about it and for some people it does not affect them, but others it does.**

2.2.3 The current, ongoing endemic stage

Several Committee members stated that people with disability, families and carers continue to make decisions based on the level of risk perceived to be associated with them. In the ongoing endemic stage, there has been a rising number of COVID-19 cases, however, masks have come off, borders opened and there has been a transition back to in-person activities and services. People with disability and their families and carers highlighted that, as a result of this, their feelings of isolation, being 'less than' and 'left behind' deepened. Committee members and many people with lived experience who were interviewed stated that the level of risks for them is higher now.

"COVID is not over. The fact that the vaccine booster is not high enough in the population makes persons with disability more vulnerable. Communications can't stop, people are still scared. [We] need to understand who to get treatment from, what to do if you get sick."

— Committee member

It was also raised by Committee members and people with lived experience that the rising COVID-19 infections prevent some people with disability from re-engaging in 'regular' activities and interacting with in-person supports and care. In interviews and focus groups, people with lived experience noted that, throughout the pandemic, there was a lack of programs, data, and response efforts to mitigate the isolation people with disability currently face.

"COVID is not over and the politics of COVID are different now. People are no longer careful, considerate, or giving people space. People are scared to go to the pharmacy to get meds because its full of people coughing without masks on. For the people who are really vulnerable, this is [a] scary time when the government seems to be doing the least effort."

— Committee member

LIVED EXPERIENCE STORY | LOSS OF SERVICES

The person with disability who I am a caregiver for lived part-time at my home and the rest of the time in a house with two other flat mates and only four hours of support worker care. When the COVID-19 lockdowns happened the two flat mates went back to live with their families and the support workers I previously used left the profession. **When I went to find new caregivers, the prices had drastically**

increased for people who had absolutely no experience with people with disability. It was a lot of stress to have lack of the normal supports I previously had, especially during such a difficult time.

When the flat mates came back after lockdown, **they had experienced the same losses of services and had worsening behaviours.** They would wake the person I am a caregiver for up in the middle of the night, causing them to not be able to sleep. **Ultimately, the person I care for had a psychotic episode and went to the hospital for inpatient treatment.** COVID-19 broke out on the hospital ward, and they locked all the patients in their rooms and seemed to stop providing appropriate psychiatric treatment. **The person I care for never tested positive for COVID-19. Regardless, the hospital started calling me 3-4 times a day, trying to transfer [them] to a COVID-19 hotel room.** The person I care for was in the middle of a psychotic episode, was not their normal self and I was worried they would seriously harm themselves if they were left alone – light matches, wrap a cord around themselves, open the window and think they can fly. When they are in the hotel rooms you cannot visit. There are so many risks of going to a hotel room during a psychotic episode.

Due to this poor care, I decided to get them from the hospital and after 17 days of being there they were still psychotic and overmedicated. Previously when this has happened, they would stay in hospital much longer. After the hospital, I had to try to get carers for nearly 24-hour care. **I had to submit a change of circumstances to the NDIS.** The person I care for is still psychotic and requiring significant supplementary care. I am now considering placing them in group home because they are requiring so much support. **They have spent nine-years partially out of home, not in a group home and living in a house with only four-hours of care a day. Now we are going to get \$140,000 from the government for the group home. This is the cost to society, to the health department. All of these people being thrust into group homes due to the pandemic. More carers being burnt out, not doing their jobs, and not receiving supports.**

2.3 People with disability are often at higher risk of COVID-19 infection and adverse outcomes

All Committee members emphasised that in health emergencies, such as the COVID-19 pandemic, people with disability are at higher risk of COVID-19 infection and adverse outcomes due to a variety of pre-existing health needs and systemic factors. These are not unique to the COVID-19 pandemic and have been longstanding contributors to poorer outcomes for people with disability.⁵ Several Committee members and state and territory government representatives noted that the COVID-19 pandemic further exacerbated these pre-existing issues and has created new barriers to adequate health care and services. For example, people with disability had already faced barriers such as lack of access to in-reach health care, and health care environments that are not inclusive, but the pandemic created new barriers including border closures which made it difficult for people to access their health care provided in other states (see Section 4).

Broader research shows that there are several factors placing people with disability at a higher risk of infection and adverse outcomes from communicable diseases such as COVID-19 (see Box 1). Additionally, several systemic factors impact access to health care or services and place people with disability at a higher risk of COVID-19 infection and adverse outcomes, including difficulty accessing quality preventative

⁵ Salomon, C.; Trollor, J. A scoping review of causes and contributors to deaths of people with disability in Australia. Exhibit 4-059-CTD.7200.0001.0060 3DN, UNSW. Report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability; University of New South Wales: Sydney, Australia, 2019.

health care,⁶ a higher rate of unemployment, economic insecurity, unsafe and insecure housing,⁷ and more common experiences of violence and abuse.⁸

Box 1 | Risks for infection and adverse outcomes from COVID-19

RISKS FOR INFECTION AND ADVERSE OUTCOMES FROM COVID-19

- People with disability are overrepresented in group settings.⁹ 1.39 million Australians with disability reported requiring assistance for one or more activities. Two in five people in prisons, aged 45 years or older, reported a disability.¹⁰
- A high proportion of the population are older with about 45 per cent (1.9 million) of people with disability are aged 65 and over.¹¹
- A high proportion of the population have chronic medical conditions.¹² Of eight selected chronic conditions studied, approximately 50 per cent of people had a disability.¹³
- People can be immunocompromised due to underlying conditions such as Down syndrome or use of certain medications.¹⁴
- The unemployment rate of working-age people with disability (10 per cent) is twice that of those without disability (4.6 per cent).¹⁵ About 11 per cent of Australians with disability were living in unaffordable housing compared with 7.6 per cent of people without disability.¹⁶

2.4 Vaccination rates for certain people with disability remain low

Some Committee members and state and territory government representatives noted concern over the low vaccination rates of certain groups among people with disability. For example, a state/territory government representative noted that there remain challenges to improve vaccination rates for children with disability (see Section 3.2.2).

By mid-August 2022, about 76 per cent of NDIS participants who were eligible for three doses of the COVID-19 vaccination had received three or more doses.¹⁷ This compares with 71.6 per cent of the general population eligible for three doses.¹⁸ However, the vaccination rates for NDIS participants aged 12-15 remained below those for the general population: 71.1 per cent of NDIS participants aged 12-15 had received at least two doses of the COVID-19 vaccine compared with 79.2 per cent for this group in the general population.¹⁹ About 88 per cent of NDIS participants living in disability accommodation had received at least two doses of COVID-19 vaccination at this time whereas about 95 per cent of aged care residents had received two doses. 85.6 per cent of NDIS participants aged 16 or over had received two doses compared with 96.20 per cent of the general population.²⁰ This data is limited by being a point in time observation.

The data discussed does not provide a complete picture of vaccination rates among people with disability as NDIS participants make up only 12 per cent of all Australians with a disability.²¹ Data on vaccination rates among people with disability who are not eligible for the NDIS is not publicly available. However, there are challenges to identifying the broader population of people with disability in existing datasets.

⁶ Salomon, C.; Trollor, J. A scoping review of causes and contributors to deaths of people with disability in Australia. Exhibit 4-059-CTD.7200.0001.0060 3DN, UNSW. Report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability; University of New South Wales: Sydney, Australia, 2019.

⁷ Australian Institute of Health and Welfare, People with disability in Australia 2022. Australian Government. 2022.

⁸ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with disability. Violence and abuse of people with disability at home issues paper. 2020.

⁹ Australian Government Department of Health and Aged Care. Management and Operational Plan for People with disability. 2020.

¹⁰ Australian Institute of Health and Welfare. The health of Australia's prisoners 2018. Australian Government. 2019.

¹¹ Australian Institute of Health and Welfare, People with disability in Australia 2022. Australian Government. 2022.

¹² Ibid.

¹³ Ibid.

¹⁴ Ram, G., & Chinen, J. Infections and immunodeficiency in Down syndrome. Clinical and experimental immunology, vol. 164 (1), pp. 9-16, 2011.

¹⁵ Australian Department of Social Services. Australia's Disability Strategy 2021-2031, 2021.

¹⁶ Ibid.

¹⁷ Australian Department of Health and Aged Care, COVID-19 vaccine roll-out update, 18 August 2022.

¹⁸ Ibid.

¹⁹ Ibid.

²⁰ Ibid.

²¹ NDIS, Who the NDIS supports. Available from: <https://www.ndis.gov.au/understanding/how-ndis-works/who-ndis-supports#:~:text=There%20are%20around%204.3%20million%20Australians%20who%20have%20a%20disability,2020>.

Some Committee members also reported that vaccine hesitancy among people with disability remains an issue, specifically when people with disability or their families and/or carers do not understand the process for, or benefits of, vaccination. A Committee member noted there has been a lack of targeted education and information to this group. Data from a longitudinal survey investigating the impacts of COVID-19 on Australian households found that levels of vaccine hesitancy were similar among people with and without disability, but higher for people with psychosocial disability.²²

One Committee member expressed great concern at what they perceived to be slowness by government agencies to explore and act on the issue of family substitute decision makers declining to consent to vaccination due to mistaken views about the benefits and risks of vaccination.

"Vaccine hesitancy is an issue, specifically by people who are family members and the proxy for other people who don't understand the process of vaccination. I would like the vaccine Taskforce to gather data to what extent this is a problem, and how to fix this problem ... there is some data showing the main causes of people not being vaccinated is personal hesitancy or carers who had substitute consent giving."

— Committee member

Broader research shows that other factors can affect vaccination coverage for people with disability too including problems securing appointments, lack of accessible information about eligibility, and finding accessible vaccination clinics.²³

2.5 The impacts of COVID-19 and the associated physical isolation for people with disability are ongoing

As noted above, the effects of the COVID-19 pandemic are ongoing. Multiple people with lived experience who were interviewed noted that they still experience significant barriers to, and increased anxiety around, resuming in-person activities and services. During the endemic and ongoing phase of the pandemic, the number of infections has increased, resulting in people with disability and their families and carers choosing to continue to self-isolate given the higher risks of contracting COVID-19. Meanwhile, many within the general population have broadly resumed normal activities.

The longer-term impacts of physical isolation and heavy restrictions across some parts of the country remain unclear, however some Committee members reported that some services supporting people with disability were lost and this loss was reported to have set people back from where they would have been or have caused them to require more intensive services than previously needed. Some people with lived experience who were interviewed reported a decline in capacity building due to the loss or delay in some of their support services.

2.6 Improved data availability and linkage will enable a better understanding of the whole-of-life or longer-term impacts of COVID-19 for people with disability

Some Committee members emphasised the lack of publicly available data about people with disability in general, and about the effects of the COVID-19 pandemic on people with disability more specifically. They noted that due to the lack of data collection and dissemination, it has been difficult to:

- understand the health needs of people with disability — while NDIS-related data is available, broader health data for people with disability is limited
- gain an accurate understanding of the COVID-19 infection rates, high risk areas for transmission, early identification and guidance of infection control interventions and outcomes of people with disability who contract COVID-19.

²² Aitken, Z, Emerson, E and Kavanagh, A., COVID-19 vaccination coverage and hesitancy among Australians with disability and long-term health conditions, 2022.

²³ Ibid.

Both Committee members and state and territory government representatives noted that data linkages that exist do not always provide meaningful insights into the impact of COVID-19 on people with disability. For example, a Committee member explained that while there has been data available on COVID-19 infections and deaths, this data does not actually determine if the person died from COVID-19 or not. As a result, it is difficult to fully interpret the available data.

"At the start of the pandemic data linkages to show this were not happening. Data is not publicly available, but we are only just now learning some things from the data. A higher proportion of people with disability experienced worse outcomes due to COVID-19."

— Committee member

One Committee member also reported there was limited data to help them understand the number and likelihood of hospitalisations, ICU stays, long COVID or other complications of infection experienced by people with disability. They explained that this in part is due to a lack of data linkage (for example, between Medicare and hospital data). Another Committee member also noted that there is lack of data collection with disability as an identifier more generally, and therefore, no inclusion of it in publicly available datasets.

"We need better data on people with disability. All vaccination forms could have had a question on if someone has a disability, but there is no widespread data collection on people with disability."

— Committee member

Overall, a strong theme that emerged from engagements with Committee members is that there is limited data available that accurately quantifies the impact of COVID-19 on people with disability. As a result, Committee members suggested that qualitative data was largely relied on to guide responses for people with disability. Improved data availability and linkage will enable a better understanding of the whole-of-life or longer-term impacts of COVID-19 for people with disability.

3 Stakeholder views of the health system responses to COVID-19 for people with disability

The following sections provide an overview of the themes that emerged around the health system response for people with disability during COVID-19 based on consultation with Committee members, state and territory government representatives and people with lived experience. Generally, those consulted reported feeling as though there had been a lack of prioritisation of people with disability in the health system response to COVID-19, leaving them without appropriate communications and limited accessibility to appropriate health system responses.

Summary of key learnings:

Committee members, state, and territory representatives and those with lived experience engaged through the process shared the following lessons learned about health system responses to COVID-19 for people with disability:

- Systemic efforts to engage people with lived experience early on to design health responses will help ensure responses are appropriately informed from the start
- Prioritising people with disability in initial health emergency responses will help ensure that they do not feel 'left behind' like they felt during parts of the COVID-19 response
- Communication of health advice to people with disability that is tailored and through the right channels will help it reach the right target groups quickly
- Communication of health advice to people with disability that is in an appropriate format will help ensure it is effectively accessed and understood
- Community-informed responses to engaging and communicating with people with disability will help enable more effective responses and better dissemination of information
- Addressing data gaps will support more targeted rollouts of vaccines and outreach for people with disability
- Continued progress towards better data capture on people with disability will enable more informed health responses moving forward
- Where good data was available on vaccinations, this was effective in guiding targeted outreach efforts
- Clearer governance arrangements between health and disability government agencies at the Commonwealth, state and territory levels will enable better health emergency responses.

3.1 Systemic efforts to engage people with lived experience early on to design health responses will help ensure responses are appropriately informed from the start

The World Health Organisation (WHO) declared COVID-19 as a global pandemic on 11 March 2020. The Australian Government published its initial COVID-19 Emergency Response Plan for the Health Sector in February 2020, a few weeks before this declaration. This plan did not mention people with disability.²⁴ The Advisory Committee on Health and Emergency Response to Coronavirus (COVID-19) for People with Disability (the Committee) was established in early April 2020. It first met on 3 April 2020.

Since the Committee's formation, it has been well regarded by Committee members and state and territory government representatives to provide the necessary attention to the issues faced by people with disability during the pandemic. It was unanimously agreed by Committee members and state and territory government representatives that the Committee has played a useful and impactful role improving and

²⁴ Australian Department of Health and Aged Care. Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19), 2020.

informing the response of the Australian Government to the needs of people with disability during the COVID-19 pandemic.

Several Committee members, state and territory government representatives believed the success of the Committee has been largely attributed to its genuine stakeholder collaboration, participation of all states, territories, and peak advisory groups with people with lived experience involved and at the centre of the engagements. This allows the committee to share insights, provide a unified response and take quick action to remedy issues.

"We need to co-design and work with people with disability from the start. People with disability need to be at the heart of every discussion and decision."

— Committee member

"Engage people with disability and make sure they are prioritised from day one."

— Person with a disability

The Committee has been vital in drawing attention to issues impacting people with disability, and as a platform for collaboration between stakeholders to advise government in their response. Generally, Committee members and state and territory government representatives felt the high level of involvement of people with lived experience, and the placement of them at the centre of the conversation and decision making was a huge part of the Committee's success. However, some Committee members noted that there are ways to improve its operation. These include ensuring:

- people with disability and stories of lived experience are at the centre of all discussions, within the Committee and subcommittees, and that they should be involved in discussions early on
- there is an optimal number of Committee members — a larger Committee means greater contribution, but at the expense of efficiency and the ability to make clear decisions at times
- sufficient funding is available to enable an adequate level of engagement by members
- discussion is wide-ranging and advice is provided on priority COVID-19 responses.

Some Committee members emphasised the preference of maintaining an ongoing Committee. However, it may be the case that the Committee would meet less often during 'normal times', and if this is not possible, there should be a plan in place to prevent any lag in reassembly of a similar committee to advise on responses to future health emergencies.

RECOMMENDATION 1:

Recognising that the COVID-19 pandemic is ongoing, the Committee should continue for the duration of the pandemic to support genuine stakeholder engagement, advise governments, and ensure people with lived experience are at the centre of future decision-making.

Beyond the pandemic, the Department of Health and Aged Care should undertake a review of the Committee, and other existing disability advisory structures in place, to determine if there is a need for the Committee to continue or if existing advisory structures are sufficient. If it is determined that the Committee should continue, it should be determined whether it should be a continuation of the current Committee, an altered version of the current Committee, or if it is merged with another group.

Any advisory structure in place beyond the pandemic needs to have broad representation of people with lived experience, experts, and other key stakeholders. However, membership should be limited to ensure inclusion is balanced with efficiency.

3.2 Prioritising people with disability in initial health emergency responses will help ensure that they do not feel 'left behind' like they felt during parts of the COVID-19 response

Several Committee members stated that Australian, state and territory governments did not adequately consult or consider people with disability as a separate group of at-risk individuals during certain parts of the COVID-19 response. Committee members believed the time period between WHO's declaration of the COVID-19 pandemic and the establishment of the Committee resulted in a lack of development of policies that addressed the needs of people with disability in the first weeks of the pandemic and some referenced findings from the Royal Commission.²⁵ In particular, Committee members stated that people with disability were not adequately considered during the initial lockdowns and in the early vaccine rollout.

3.2.1 The need to prioritise people with disability during initial lockdowns

Committee members said that inadequate consultation with people with disability in the initial weeks of the pandemic, before the Committee was formed, resulted in a lack of consideration for people with disability when state and territory lockdown restrictions were first implemented. For example, one Committee member recounted hearing stories where people had to break lockdown restrictions to ensure appropriate care of people with disability who otherwise would have been in unsafe situations due to loss of their essential support services. Some Committee members also reported there was significant confusion arising from the lack of definition around essential services and information on services permitted to continue during lockdowns, in some jurisdictions.

Several representatives of service providers reported not being provided with timely clarification from governments about new policies and restrictions, which affected the support and services provided to people with disability. They also reported slow responses when they lodged inquiries for further information. Some service providers said they had to interpret guidance themselves and make decisions on what services to provide. They reported this to be costly and time consuming. It also led to variability in the supports and services provided to people with disability.

"It has been a heavy workload. We are meant to decide when and who people can engage with during COVID. The government was not proactive in telling us. Administration wise, it was an absolute nightmare. Sometimes you would make one decision on information and then have to immediately change it."

— Service provider

3.2.2 The need to prioritise people with disability during the early vaccine rollout

Committee members stated that the rollout of COVID-19 vaccinations for people with disability and workers was inadequate, with many references to the findings from the Royal Commission,²⁶ however, since then, improvements have been made. In January 2021, the Australian Government published the COVID-19 Vaccine Rollout Strategy (the Strategy), which outlined priority populations including disability care residents and workers.²⁷ The Strategy indicated that disability care residents and workers would be vaccinated on-site at their supported accommodation service by contracted 'in-reach' vaccination providers. However, Committee members referenced the Royal Commission finding that people in disability residential settings were deprioritised during the actual vaccination rollout process.²⁸ Committee

²⁵ Royal Commission into violence, abuse, neglect, and exploitation of people with disability. Public hearing report 5: experiences of people with disability during the ongoing COVID-19 pandemic. 2020.

²⁶ Royal commission into violence, abuse, neglect and exploitation of people with disability. Public Hearing Report 12. The experiences of people with disability, in the context of the Australian Government's approach to the COVID19 vaccine rollout, 2021.

²⁷ Australian Department of Health and Aged Care. Australia's COVID-19 vaccine national roll-out strategy, 2021.

²⁸ Royal commission into violence, abuse, neglect and exploitation of people with disability. Public Hearing Report 12. The experiences of people with disability, in the context of the Australian Government's approach to the COVID19 vaccine rollout, 2021.

members noted that the deprioritisation of vaccination increased confusion among people with disability during the initial stages of vaccine rollout.

Committee members and people with lived experience noted that the vaccine rollout was particularly challenging for children with disability and their families and carers. For example, a Committee member recounted a story they heard of a parent being told by their GP that their child with Down syndrome did not need to be vaccinated because they were not in an at-risk group. A carer who was interviewed also noted difficulties obtaining vaccination for their child with disability. They reported being told that children in general are a lower risk group and that they felt their child's disability was overlooked. The carer said this in part was due to ATAGI being initially unclear on whether children with disability should be prioritised for vaccination.

"ATAGI defined adults with a disability to be a priority group. But for children, it was initially vaguer, and it was left up to individual health practitioners to advise on whether a child should be eligible for priority access to vaccines – ATAGI have now revised to 'significant health need', which clearly includes children with rare genetic orders, Down syndrome, but it's silent on autism – most children don't have a physical disability."

— Person who cares for a child with disability

Overall, Committee members and people with lived experience stated that the inadequate consideration by governments for people with disability, their families and carers, and workers during lockdown and vaccination rollout resulted in confusion, fear, loss of the proper supports and ongoing vaccine hesitancy. Some Committee members and state and territory government representatives attributed this failure to be largely due to a lack of oversight, data and understanding of people with disability, the settings they live in, the location of supported accommodation services and their unique and varied support needs. These needs include, for example, low sensory vaccination environments, strategies to minimise fear of needles and, where necessary, sedation.

3.2.3 Ensuring people with disability do not feel 'left behind' like they felt during the initial COVID-19 response

Several Committee members noted that people with lived experience of disability felt forgotten and left behind in all aspects of the health system response from the start — as though they were an 'afterthought'. Several people with disability spoke about not hearing media information or press releases that were specific to disability and instead disability was referenced through the use of the term 'vulnerable groups'.

"Using the word vulnerable instead of disability is a huge lesson to be learned. People need to recognise disability. People in the community report feeling like they are not being looked at or heard."

— Person with a disability

Many Committee members and people with lived experience noted that the delay in publication of Easy Read materials and consultation arrangements for and with people with disability were set up too late. They stated that the vaccination rollout was 'disappointing' and that it 'sent a massive message to the community' making them feel 'left behind' and 'less significant' than others.

Almost all Committee members commented that the Department of Health and Aged Care seemed to focus more on aged care than on the disability sector. They reported that this led to an emphasis on aged care with people with disability left behind.

"People with disability were not commonly accepted to be more vulnerable in government communications and have been left behind even still with ongoing COVID. They are at greater risk of morbidity and mortality and are important to remember. With the emphasis that has been on aged care, the persons with disability have been forgotten."

— Committee member

A key learning for health departments moving forward is to ensure health responses adequately prioritise, assess and address the diverse needs of people with disability. This will ensure they do not feel 'left behind' like they had felt in the initial COVID-19 response.

RECOMMENDATION 2:

The Department of Health and Aged Care and state and territory health departments should jointly commit to the development of a comprehensive strategy that would include an immediate needs assessment for people with disability during health emergencies, such as pandemics. For people with disability identified as a high-risk group, with high healthcare needs, the strategy should:

- categorise them as high risk and commit to prioritisation of their health needs in the response
- explicitly call out what is required and what supports are available for this group in health directives and communications.

The Australian, state and territory governments should execute this strategy to ensure the health and social needs of people of disability are addressed in current and future responses to health emergencies.

RECOMMENDATION 3:

The Australian Government and state and territory governments should continue to fund and deliver policies and programs to increase the vaccination rates for people with disability. This requires emphasis on the ongoing nature of the COVID-19 pandemic, targeted outreach to families and/or carers who help make health care decisions for children and people with disability, and accessible information and a range of options for vaccination supports including low sensory environment, sedation and vaccination clinics. Additionally, the Australian Government should continue to provide vaccine prioritisation and prioritised access to infection control/prevention knowledge and training for people with disability, their families and carers, and workers in close contact with people with disability.

3.3 Communication of health advice that is tailored and through the right channels will help it reach the right target groups quickly

Several Committee members reported that the Australian, state and territory health department responses and communication of information were initially slow, and did not always reach target groups quickly enough. Communications were reported to be limited by the inability to target people with disability 'as a

"A person who is an amputee would have a different set of needs than a person with respiratory disability. [There are also different support and] accommodation settings. Even if you are at home, you may have 10 people coming into your home, which might be the same as in a residential facility. But there are different public health regulations between the two."

— Committee member

group'. Committee members noted that this is in part because health departments often do not have direct inroads into engaging or communicating with people with disability as a whole cohort across Australia. A Committee member reported the Department was initially unfamiliar with how to leverage existing communication channels to target people with disability, for example, working in partnership with peak bodies and disability providers to share key messages. However, Committee members highlighted that this improved over time.

Committee members noted that channelling COVID-19 communications through the NDIA and the Department of Social Services only reached some people with disability. This meant many people with disability who are not already accessing funding through these agencies were missed. People with lived experience also reported that some communications that they received were inadequate. For example, one Committee member noted that reaching information sometimes involved scrolling through multiple website pages and inaccessible information.

This is a problem both for the response (for example, who do you vaccinate if you are prioritising 'people with disability') and communications (for example, who do you send tailored updates and information to).

Committee members, state and territory representatives and people with lived experience noted that there is a need to better understand how people with disability, their families and carers, and workers receive most of their information and to tailor the available information to reach the target cohort effectively.

RECOMMENDATION 4:

The Australian, state and territory health departments, in partnership with the Committee, should develop well-informed communication plans and strategies to ensure health advice reaches people with disability quickly during future health emergencies. Health departments should:

- lead the messaging on health advice but engage with partners who work in and/or understand the disability sector (for example, peak bodies, the NDIA and DSS) to establish communication plans to distribute health advice
- document and maintain established partnerships, networks and communication channels (including those developed during COVID-19) for the duration of COVID-19 and beyond for ongoing communications and for when other health emergencies occur.

3.4 Communication of health advice that is in an appropriate format will help ensure it is effectively accessed and understood

Committee members and people with lived experience stated that communication of public health advice and health responses was initially in unsuitable formats for people with disability. Some Committee members noted that communication avenues that people with disability often used did not contain the right or relevant instructions and information. Service providers in the sector, and staff of supported accommodation services said that interpreting information published by the Department of Health and Aged Care was complicated and required a lot of time and cost to the organisation. People with lived experience reported that overall, information was difficult to find, and not in the desired format.

"The department did not have experience or ability to develop [communications] in Easy Read. They had to establish those networks. Communicating [information] in a way that was accessible to people with disability is a challenge. Producing informational products was hard and had to cover different topics, use different channels. They had a lot of unique needs and questions."

— Committee member

"Information needs to be provided in multiple formats, in ways people want to engage with the material."

— Committee member

People with lived experience who were interviewed reported receiving their information from watching television but stated that the information provided was hard to understand.

Several Committee members noted that the Department of Health and Aged Care has responded well to this feedback and communications and has improved them and their relationships with communication channels over time. They also emphasised the importance of maintaining relationships created to disseminate information during COVID-19 to expand the availability of approachable information to people with disability, even outside of the pandemic and emergency responses.

"Messages given on TV are for general populations. It would be great if they could send out messages to group homes from these people. Daniel Andrews was beloved by our house residents, but the messaging was complex. We would have meetings after TV information to discuss what it means. We really need more direct and specific messaging for people with intellectual disability."

— Person with a disability

RECOMMENDATION 5:

The Australian, state and territory health departments, in partnership with the Committee, should ensure all communications targeted towards people with disability are in formats that people with disability want to and can engage with. All communications related to COVID-19 and future health emergencies must be available in multiple formats, including Easy Read and be available at the same time as general advice.

3.5 Community-informed responses to engaging and communicating with people with disability will help enable more effective responses and better dissemination of information

Many state and territory government representatives reported that use of local hospital networks and disability organisations 'on the ground' were most effective in identifying, communicating with, and informing responses for people with disability. As there is no national data set on all people with disability, and where they live, work, or receive their information from, community-informed responses by people who already have trusted relationships with people with disability were found to be most influential.

Some state and territory government representatives noted that in situations where existing community networks and relationships were leveraged to support health responses, better dissemination of information occurred. This includes working with local schools, community centres, and local health and disability support providers.

RECOMMENDATION 6:

The Australian Government and state and territory governments should ensure existing community networks and relationships are documented and leveraged to support responses to health emergencies. Use of existing community resources and networks is a useful lever to communicate with people who may be difficult to reach, to spread information, support health responses and design adequate supports to address their needs.

3.6 Addressing data gaps will support more targeted rollouts of vaccines and outreach for people with disability

Committee members and state and territory government representatives noted that data limitations made the vaccine rollout and outreach challenging.

One state/territory government representative attributed the lack of data to poor government oversight of disability support needs, and services accessed by people with disability. A Committee member also noted that there is a gap in data collection on disability service provider identities, such as in the case of registered NDIS providers and non-registered allied health providers. In cases where data does exist, it is not easily consolidated, being scattered across different Australian, state and territory government datasets.

For people with disability and those that work closely with them, a strong theme arose among Committee members who felt the Department of Health and Aged Care was not able to have clear oversight of the services, where they are located, and who uses, lives and/or works within them. Moreover, the characteristics of supported accommodation services for people with disability are different than for aged care. It was reported by some Committee members that this was not well understood, resulting in slow outreach.

Overall, several Committee members and state and territory government representatives felt that the lack of pre-existing data on people with disability, and their support workers, led to difficulty reaching this population and to inform responses during the pandemic. Committee members also noted that this led to delays in vaccination rollout and referenced similar findings from the Royal Commission.²⁹ They also noted that data gaps extend to a lack of information on the whole-of-life or longer-term impacts of COVID-19 for people with disability (discussed in Section 2.6).

A key learning of Committee members and state and territory government representatives is that these data gaps will need to be filled to support more targeted rollouts of vaccines and outreach for people with disability moving forward, and for future health emergencies.

3.7 Continued progress towards better data capture on people with disability will enable more informed health responses moving forward

Before the COVID-19 pandemic, the National Disability Data Asset (NDDA) was named a Commonwealth, state and territory joint initiative following an agreement by the Australian Data and Digital Council in 2019. The objective of the NDDA is to develop a cross-jurisdictional dataset that can help governments understand the life and outcomes of people with disability.³⁰ The pilot commenced in April 2020 and initial data is planned to incorporate linkage of numerous datasets across Australia to provide a better understanding of how people with disability are supported through services, payments, and programs

²⁹ Royal commission into violence, abuse, neglect and exploitation of people with disability. Public Hearing Report 12. The experiences of people with disability, in the context of the Australian Government's approach to the COVID19 vaccine rollout, 2021.

³⁰ Australian Department of Social Services, Australian Government. NDDA Disability Advisory Council meeting communiqué. July 2020, 2020.

across multiple service systems. The pilot phase is now complete, and the Commonwealth and state and territory governments are working on the design for the next phase. This will involve consultations with people with disability and the broader disability community to support the design of the asset.³¹

While having a comprehensive disability dataset will improve data availability, Committee members said it was unclear if the NDDA has plans to specifically address the data gaps related to the pandemic. During consultations, it was noted by some state and territory government representatives that they have successfully developed their own linked datasets to address COVID-19 related data gaps. For example, Victoria has recently presented data on hospitalisations of people with disability to the Royal Commission. However, the data was not publicly available at the time of this report.

Other jurisdictions, such as the Northern Territory, also reported having their own data that helped guide responses during COVID-19. Due to their unique population and demographics with a higher proportion of remote, Aboriginal and Torres Strait Islander people, the Northern Territory collects data and information on the location of all vulnerable people in remote communities. This was reported to enable them to plan and respond in a more informed manner during emergencies, such as the pandemic.

The Committee's disability data working group also provided and presented data to the Committee to assist in decision making and inform discussion.

One Committee member noted that real-time data on COVID-19 infections for people with disability could have helped identify high-risk areas of transmission. They felt responses could have been guided by this data for faster infection control and prevention in services or supported accommodation services. Another Committee member recommended that future data linkages and data collection should focus on the impacts of COVID-19 for people with disability such as deaths, hospital and ICU admissions and long COVID-19 statistics.

RECOMMENDATION 7:

The Australian Government and state and territory governments should continue to invest in improving data collection and linkage that inform policies, programs and services that affect people with disability and support a better understanding of the effect of COVID-19 on people with disability, including ongoing effects such as long COVID. This data should be shared between the Commonwealth, state and territory governments, and where possible, with people with disability; and it should be updated frequently enough to support informed decision making.

3.8 Where good data was available on vaccinations, this was effective in guiding targeted outreach efforts

There is a significant amount of data on NDIS participants, including data on vaccination statuses of participants which is publicly available.³² This data was reported by some Committee members to benefit and help provide more targeted vaccination outreach efforts. As at 28 July 2022, 85.8 per cent of NDIS participants over the age of 16 had received at least two doses of the COVID-19 vaccine.³³ When data was available, it was reported by a Committee member that it was used to help guide vaccination response and other interventions.

Committee members and state and territory government representatives spoke of programs that increased vaccination rates including targeted text messages sent to NDIS participants identified as unvaccinated to help support them to find vaccination sites, resources, or providers. A Committee member quoted a 72 per cent increase in calls to obtain vaccination information two weeks in a row since targeted text messages were sent. The Queensland Government also ran a similar texting campaign for all residents

³¹ Australian Department of Social Services, Australian Government. The National Disability Data Asset, 2022. Available from: <https://ndda.dss.gov.au/about-orig/the-ndda/>

³² NDIS. Australia's COVID-19 Vaccine Rollout delivers high vaccination rates among people with disability, 2021.

³³ Australian Government Department of Health and Aged Care. COVID-19 vaccine roll-out update, 31 July 2022, 2022.

and noted that once vaccination data was shared with them, they were able to act on that information quickly to promote vaccination rates.³⁴

3.9 Improved coordination between health and disability government agencies at the Commonwealth, state and territory levels will enable better health emergency responses

Committee members and state and territory representatives raised that the unclear roles and responsibilities between the Department of Health and Aged Care and state and territory health departments contributed to unclear communications, poorer outreach capacity and uncoordinated responses.

“Outreach did not work well and there was a lack of comms – feels like the Department of Health [and Aged Care] and state/territory health department divide showed in this because some services are only provided by states/territories and the Commonwealth didn’t have the information on what was going on. There were different offerings between states/territories.”

— Committee member

“There is a lack of clinical expertise in the area of disability care. There is a lack of framework and knowledge within the sector.”

— State/territory government representative

While health and disability government agencies serve different purposes and have clearly defined roles and responsibilities, it was reported by Committee members and state and territory government representatives that unclear governance arrangements regarding the COVID-19 response between government health and disability agencies created barriers for government responses. A common theme raised by Committee members and state and territory government representatives was that there are ‘huge gaps’ between health and disability and ‘areas of grey’ around where health care services start and finish, and what disability services do. Committee members expressed that there is a lack of understanding within health agencies on just how poor the health of people with disability can be, and there is a lack of clinical expertise in disability care.

While these shortcomings in governance arrangements were acknowledged, it was also recognised by Committee members and state and territory representatives that the roles and responsibilities of health and disability agencies are clearer now and there are good examples of coordination between Australian, state and territory governments. A state/territory government representative also noted that good linkages were established throughout the pandemic between areas of both state and territory, and Commonwealth governments, and that these should continue and aid in other responses for people with disability going forward.

RECOMMENDATION 8:

The Australian Government and state and territory governments should develop and agree on governance arrangements for health responses for people with disability during health emergencies. While health agencies are responsible for leading the health response, there should be governance structures in place that identify supporting agencies and clarify their role in supporting the health response. For people with disability, this should include the Australian Department of Social

³⁴ Minister for Health and Ambulance Services, Queensland Government. Millions set to receive a text from the government in new vaccination push, Media Statement 04 October 2021, 2021.

4 Stakeholder views of the health service and program responses to the COVID-19 pandemic

The following sections focus on and detail the specific health service and program level (rather than system-wide) responses during the COVID-19 pandemic that were commented on by Committee members, state and territory government representatives and people with lived experience. Strong themes emerged surrounding the benefits of telehealth during COVID-19 to assist people with disability maintain access to health care services. Additionally, there were models of care such as in-reach vaccination, disability liaison officers, and GP home visits that were reported to effectively accommodate the needs of people with disability.

Summary of key learnings:

Committee members, state, and territory representatives and those with lived experience engaged through the process shared the following lessons learned about health service and program responses to the COVID-19 pandemic for people with disability:

- In-reach vaccination and health service provision will enable more accessible services for people with disability
- Providing people with disability with options to access virtual and telehealth services will support more accessible health care provision
- Health liaison roles and community-based programs will enable better communication and reach with people with disability
- Improvements to existing models of health care can enable more accessible and effective health care for people with disability.

The lessons learned above particularly apply to health emergencies, but many of those consulted with emphasised the need for these learnings to be considered beyond health emergencies as well.

4.1 In-reach vaccination and health service provision will enable more accessible services for people with disability

Committee members, and people with lived experience stated that many people with disability feared going to health care facilities, including their GP, and participating in daily activities due to concerns that they may contract COVID-19.

For this reason, it was reported that GP home visits and in-reach vaccination were beneficial for people with disability during COVID-19 because they enabled more accessible health care for them.

Some Committee members and state and territory government representatives noted the in-reach vaccination program worked well and met the needs of people with disability initially. However, there was a change in availability of in-reach vaccination for the third and fourth doses of the COVID-19 vaccine. This caused confusion among people with disability regarding where to get their vaccination and one Committee member felt it contributed to lower rates of booster vaccination initially.

A few Committee members also stated that GP home visits worked well and provided tailored, personalised health care services for people with disability during COVID-19 as it meant limited travel, and promoted social distancing. However, one Committee member reported that GP home visits are limited to certain practices and hospital systems and rarely occur as they are not well incentivised by current funding

models. An example of a home visit program introduced in response to COVID-19 is the North Western Melbourne PHN's program to provide GP, practice nurses and respiratory clinic health care to people who have contracted COVID-19, are living with a COVID-19 positive person, or are with a disability and/or housebound who cannot attend routine care.³⁵

4.2 Providing people with disability with options to access virtual and telehealth services will support more accessible health care provision

Telehealth is the delivery of health care services via electronic methods such as a telephone or video conferencing. Telehealth existed before COVID-19, however funding for it and demand for it drastically expanded during COVID-19.³⁶ Committee members reported that telehealth became a popular model of health care service delivery during COVID-19 for people with disability and there was widespread use of the services. It was also reported to assist in maintaining services during lockdowns when there were restrictions on service provision.

Committee members and state and territory government representatives reported that telehealth has been an effective alternative to in-person care and has allowed people with disability to safely maintain their access to health care. Additionally, they noted that telehealth can decrease health professionals' travel time, increasing the number of consultations they are able to perform per day. Committee members also emphasised that the benefits of telehealth, in improving access to health services for people with disability, extend beyond the context of the pandemic.

However, Committee members also noted that face-to-face care and services are still important and certain services or health care appointments are not appropriate for prolonged engagement via telehealth. One example provided by a Committee member was physiotherapy, which was felt to be inadequately delivered by telehealth. Additionally, if telehealth services are not implemented in an inclusive manner (for example, without support for internet access, accessibility features, or availability of interpreters) it could lead to greater health care service inequities.

"Eventually some of the services they were able to do virtually. [They] still do speech therapy virtually because [they] really liked it. Telehealth could not replace [their] physio, which was his favourite."

— Committee member

While telehealth has some limitations, it has been an effective service option allowing people with disability to safely access health care during the pandemic. A person with lived experience had raised concerns that funding for telehealth services may be discontinued beyond COVID-19.

"Telehealth was a huge gain. It is really sad to hear it is getting wound back and won't be available again. It opened up a lot of services for people who have difficulty leaving the house. It also made these activities more independent for me. I am able to see a psychologist and don't need to coordinate someone to drive me. I would really encourage them to make that widely available, not just through a pandemic."

— Person with a disability

The Australian Government has confirmed MBS telehealth arrangements will remain in place from 1 July 2022, with a new prescribed pattern of service expected to commence on 1 October 2022.³⁷

Another virtual care model referenced by Committee members was the COVID-19 National Helpline. The COVID-19 National Helpline is accessible to all, but includes screening for specific conditions so that tailored and appropriate information can be provided. This phone line is available 24 hours a day, 7 days a week.³⁸ It helps provide information on vaccination clinics and locations.

³⁵ North Western Melbourne Primary Health Network. COVID-19 home visit program. Available from: <https://nwmphn.org.au/for-primary-care/covid-19/>, 2022.

³⁶ Australian Department of Health and Aged Care. Providing health care remotely during the COVID-19 pandemic, 2022.

³⁷ Australian Government Department of Health and Aged Care. MBS Telehealth Services from 1 July 2022, 2022.

³⁸ Australian Government Department of Health and Aged Care. National Coronavirus Helpline, 2022.

While the COVID-19 National Helpline was reported by a state/territory government representative to be successful when used as a resource to assist in increasing vaccination awareness and information, it sometimes provided conflicting information due to the different COVID-19 responses between states and territories. The state/territory government representative felt that this in part could be because no dedicated overarching body was responsible for overseeing and communicating with people with disability and to help them navigate the differing services and restrictions across states and territories.

RECOMMENDATION 9:

The Department of Health and Aged Care should maintain telehealth services for people with disability, particularly those who may face access barriers to in-person health care. Additional supports should be put in place to enable people with disability to access and use telehealth appropriately.

4.3 Health liaison roles and community-based programs will enable better communication and reach with people with disability

Committee members and state and territory government representatives reported that responses and engagement with people with disability were most successful when they were flexible and responsive to individual settings and needs, rather than general and prescriptive. Numerous Committee members noted that community-based programs were most effective during the COVID-19 pandemic. While some of the services were created in response to the COVID-19 pandemic, others served a different purpose pre-COVID and were able to pivot their services during the pandemic to the emerging needs.

Committee members shared examples that they thought were good practice models of care for people with disability, such as the Disability Liaison Officer (DLO) program in Victoria. One Committee member noted the DLO helped people with disability better navigate services including vaccination programs during the COVID-19 pandemic. The DLO has been a primary contact point for people with disability to provide support and access to both COVID-19 and non-COVID-19 related assessment and treatment.³⁹

"Victoria's disability liaison officers are a successful model. They engage at a local level with people with disability. They then tackled local level, individual problems to navigate the system."

— Committee member

The COVID@home program in Tasmania was also highlighted as another good practice example. This program provided meaningful support in the community when family members were ill with COVID to stakeholders consulted. The COVID@home clinical response team provided remote health care in the home 24 hours, 7 days a week. It was reported that part of this program was personalised for people with disability. The Disability Emergency Operations Centre (DEOC) flagged and prioritised people with disability for programs, and educated staff on the unique characteristics, needs and risks associated with people with disability.

Several Committee members and state and territory government representatives noted that while these health liaison roles and community-based programs worked well, there is no wider coordinated effort to fund or support them across states and territories, and that many people with disability did not have access to these programs or similar services.

Additionally, despite the success of programs reported anecdotally by Committee members and state and territory government representatives, there are no evaluations of these programs.

³⁹ Victorian State Government. Disability Liaison Officers making COVID-19 vaccinations easier for people with autism, 2021

RECOMMENDATION 10:

The Australian Government and state and territory governments should work together to ensure that liaison roles and community level responses are well supported, empowered, and equipped for future health emergencies. The governments should develop clear guidelines for liaison roles and responsibilities and provide them the tools they need to perform effective community outreach and interventions.

4.4 Improvements to existing models of health care can enable more accessible and effective health care for people with disability

Several Committee members and state and territory government representatives believe the pandemic has shown there is scope to improve current health care approaches to better accommodate the needs of people with disability more broadly. Committee members emphasised that people with disability faced numerous barriers to accessing appropriate health care before COVID-19, but these barriers were exacerbated during the pandemic. A common theme among Committee members was that prior to the COVID-19 pandemic, there had been little done in this space.

"Response to the pandemic was made less effective by the issues that were already in place such as the funding issues etc. The COVID-19 pandemic exacerbated and showed those issues. It showed people working within a system they didn't actually understand. We need to take into account the systemic issues or else these issues will simply be repeated in the future."

— Committee member

It was stated that people with disability face barriers to accessing health care, and health care that is accommodating to their needs. In particular, different Committee members raised that:

- there is a lack of in-reach health care, for example through GP home visits
- health care environments and infrastructure may not be inclusive, for example, waiting rooms in hospitals are often bright, loud and busy, which is not accommodating for some people with intellectual disability
- health services do not always have the capacity to improve access to health care and address the health needs of people with disability
- people with disability may have health care needs that require long distance travel to specialised health care centres that is impacted by border closures and quarantine.

"Existing models of care do not work well currently. The health system does not engage with people with disability as a group. It has been down to the individual and the support that individual has around them."

— Committee member

While Nous does not have enough information to make recommendations on the broader health care system for people with disability, these insights were a strong theme throughout all consultations. They should be reviewed and considered by the Australian Government and state and territory governments.

As discussed above, there are some good practice examples of models of care for people with disability that aimed to improve the capacity of health services to better address the health needs of people with disability, for example telehealth and the Victorian DLO program. These services were all highly regarded

by Committee members and state and territory government representatives who believed they improved the COVID-19 experience with health care services.

Committee members also discussed the importance of having clinical practitioners involved in consultation with people with disability in hospital settings. A strong theme was the importance of equitable access to health care services, the ability to communicate clear advance care directives for COVID-19 treatment and the ability to have a family member, carer or support worker present/consulted for information in the hospital setting, as needed.

"COVID plans need to be in place for each person with disability so it is clear what treatment and support will be used."

— Committee member

The Queensland Government representatives highlighted the state's initiatives pre-COVID to better address the health care needs of people with intellectual or cognitive disability. The Julian's Key Health Passport program was implemented for people with disability to be able to provide care information in a format that is easily shared with health staff. Additionally, the Comprehensive Health Assessment Program (CHAP) was also utilised to help minimise the barriers to healthcare for people with intellectual disability. The program involves a questionnaire that documents the consumer's health history and provides the GP with prompts and guidelines relating to health issues. The Queensland Government provides CHAP free to eligible individuals via request from other service providers, including GPs or allied health professionals.⁴⁰ These programs were promoted, and their use pivoted during COVID-19 to be used alongside Hospital Companion documentation as part of the COVID-19 health care rights for people with disability.⁴¹

One Committee member reported interest in having access to similar programs to be able to clearly provide advance care directive and desired treatments, should they become ill with COVID-19.

Committee members noted opportunities to leverage off the scale and reach of COVID-19 health responses to improve access to other important health interventions for people with disability. For example, one state/territory government representative stated that in-reach vaccination programs for COVID-19 missed opportunities to also deliver and/or connect people with flu or other vaccinations. They argued that the pandemic allows for better contact with individuals, and a person's holistic health needs can be considered to capitalise on opportunities to improve their general health.

Other examples highlighted by Committee members come from the Human Rights Framework that describes the right to accessible information, full inclusions, and provision of choice as well as access to appropriate communications.⁴²

These are lessons that can be considered for appropriate and equitable access of health care for people with disability more broadly.

CONSIDERATION 1:

The Australian, state and territory health departments should undertake their own reviews of current health service models to understand existing barriers and challenges for people with disability in accessing and receiving health care that meet their needs, as well as the underlying drivers of this inequality, as part of future health emergency responses. Departments should also review and consider good practice examples of health care models that:

- support people with disability and their families and carers to access appropriate health care
- support health care teams and hospitals to provide safer, more inclusive health care to people with disability

⁴⁰ Queensland Government. Comprehensive Health Assessment Program. Last updated 22 July 2022.

⁴¹ Queenslanders with Disability Network. Know your rights: A guide for people with disability to get the hospital care they need during COVID-19, 2021.

⁴² Australian Human Rights Commission. Guidelines on the rights of people with disability in health and disability care during COVID-19, 2020.

- assist people with disability in contact with health care services access other services they may need
- continue in-home testing and in-reach vaccination programs, including for COVID-19
- support decision making for people with disability and their families and carers, including in situations where there is a guardian who is responsible for decision making.

5 Stakeholder views of the role of sectors outside of health

The following section discusses how sectors outside of health responded during the COVID-19 pandemic, and how their responses affected people with disability as commented on by Committee members, state and territory government representatives and people with lived experience. This includes disability and human services agencies, education departments and police. Through these engagements, lessons were identified around how these sectors could better support people with disability moving forward and in future health emergencies.

Summary of key learnings:

Committee members, state, and territory representatives and those with lived experience engaged through the process shared the following lessons learned about the role of other sectors in the COVID-19 response for people with disability:

- Temporary support measures and more flexible support for people with disability, through the NDIS, will enable more appropriate responses to health emergencies
- Improved understanding, communication and coordination of the roles and interface between the NDIS Quality and Safeguards Commission and Department of Health and Aged Care during health emergencies will enable better and more efficient responses
- Practice standards specified for pandemics, that have been in place since November 2021, for NDIS providers, will guide responses during health emergencies
- Ensuring e-learning methods in schools are accompanied with appropriate support will improve accessibility for children with disability
- Training police in disability inclusion practices will enable more informed enforcement of public health measures.

Committee members and state and territory government representatives stated that while health departments are key responders during health emergencies, including COVID-19, a coordinated response with other sectors and other government agencies is required as well. Examples were provided where health departments were able to work collaboratively with other agencies including education, police, and human services. However, there was broad recognition across Committee members and state and territory government representatives that cross-agency collaboration, and responses to the pandemic introduced by non-health agencies, could have better supported people with disability.

5.1 Temporary support measures and more flexible support for people with disability, through the NDIS, will enable more appropriate responses to health emergencies

The NDIS provides funding for supports and services for more than 500,000 Australians who have a permanent and significant disability.⁴³ That is, only a small proportion of people with a disability receive a funded support package through the NDIS. However, Committee members and people with lived experience reported problems and lessons learned specifically for NDIS participants and providers. These are explained further below and in the following sections.

In response to the COVID-19 pandemic, several temporary COVID-19 measures to support NDIS participants and providers were implemented. For NDIS participants, this included funds to purchase PPE

⁴³ NDIS, Who the NDIS supports, 2020. Available from: <https://www.ndis.gov.au/understanding/how-ndis-works/who-ndis-supports#:~:text=There%20are%20around%204.3%20million%20Australians%20who%20have%20a%20disability.>

for their support worker, a one-off deep clean of their home, meal preparation and delivery, rapid antigen tests (RATs), and assistive technology (such as fitness equipment).⁴⁴ One person with lived experience also reported that there was some flexibility to move 'capacity' support to 'core' support, but the communication around this was initially unclear. Temporary payments were also made to eligible NDIS providers to support participants arrange and receive their vaccinations.

Some Committee members acknowledged these additional temporary supports and highlighted their benefits, but also raised that it is unclear when they will expire.

Despite the temporary measures provided by the NDIS during COVID-19, Committee members and people with lived experience reported that NDIS plans remained inflexible for some — and people were not able to access additional supports they needed. One carer who was interviewed stated that it was difficult to access additional support if they fell sick and could not provide their usual level of support for the person they cared for.

"NDIS needs to have crisis care. [I know a] mother of six who got COVID, and her son got COVID. [They needed extra support but a] review of a NDIS plan change takes 3-6 months. There was no ability for people like that to get supports for a week or two while they were sick/family was in crisis."

— Committee member

"I wish there was someone I could call to say 'hey I am struggling I need some help' I wish that existed. Not just talking help, but someone to come in and physically help. My son when he gets sick, he needs nebulisers, chest percussions and other supports, but I was so short of breath with COVID I could barely walk. It was hard to keep him out of the hospital because I was so sick myself."

— Person who cares for someone with a disability

A key learning of Committee members and people with lived experience is that more flexible NDIS plans, and discretionary funding, would help support participants better during health emergencies, such as pandemics.

RECOMMENDATION 11:

The NDIA should ensure NDIS plans are flexible enough to support NDIS participants during health emergencies, such as the COVID-19 pandemic. In these situations, participants may require increased financial support for additional services, such as a temporary support worker in cases where their family care giver becomes ill.

5.2 Improved understanding, communication and coordination of the roles and interface between the NDIS Quality and Safeguards Commission and Department of Health and Aged Care during health emergencies will enable better and more efficient responses

The NDIS Quality and Safeguards Commission was established to improve the quality and safety of NDIS supports and services. It undertakes a range of functions that are prescribed in the *NDIS Act 2013* (Cth) including, regulating NDIS providers, responding to complaints, monitoring and securing compliance against the NDIS Code of Conduct and Practice Standards, and promotes best practice to providers.

⁴⁴ NDIS, For participants – coronavirus (COVID-19), 2022. Available from: <https://www.ndis.gov.au/coronavirus/participants-coronavirus-covid-19>

Some Committee members reported that there was a lack of understanding and communication around what role the NDIS Quality and Safeguards Commission plays, and that the Commission took a 'cautious view of their role'. References were made to the Royal Commission finding that the NDIS Quality and Safeguards Commission relied on the pre-existing Practice Standards and policies to respond to the pandemic, and that this was not sufficient.⁴⁵

"What is the NDIS Quality and Safeguards Commission's responsibility in ensuring providers are compliant? Feels like it is complaints-based rather than proactive. Services were left on their own because the NDIS Quality and Safeguards Commission were not prepared."

— Committee member

Several Committee members also raised that it was not always clearly communicated, understood or coordinated in practice what the roles and responsibilities of the NDIS Quality and Safeguards Commission are and what should be responsibilities of the Department of Health and Aged Care or the NDIA. Committee members reported feeling that at times, there was a lack of visibility and understanding of which agency was doing what.

"What are the responsibilities of the different agencies in this response ... I think the NDIS Quality and Safeguards Commission and the NDIA need better understanding of health/public health so they're talking at the same level [as health departments] ... Feels like each agency passes it on to the other. Bureaucratic and system failures get in the way as these agencies all pass the buck to one another."

— Committee member

The NDIS Quality and Safeguards Commission provided information for this report about a range of activities and actions that it undertook, under its regulatory functions and powers, since the early stages of the COVID-19 pandemic. This includes providing information and guidance for NDIS providers and participants and establishing systems for monitoring and responding to the impact of COVID-19 on providers and participants. National compliance programs have focused on supporting participant access to vaccination and mandatory worker vaccination requirements. The NDIS Quality and Safeguards Commission advised that these programs have involved more than 12,000 NDIS providers, and compliance and enforcement action related to COVID-19 has been taken for over 200 NDIS providers and workers who were identified as not complying with obligations under the *NDIS Act 2013* (Cth).

RECOMMENDATION 12:

The NDIS Quality and Safeguards Commission, in consultation with the Department of Health and Aged Care, should improve understanding, communication and coordination of their roles and responsibilities during health emergencies and obligations of providers to provide high-quality NDIS supports consistent with their obligations under the *NDIS Act 2013* (Cth). This should include clarifying responsibilities for educating and building capability of providers to respond safely during health emergencies, and in ensuring compliance with health requirements and mandates. Clarified roles and responsibilities should be effectively communicated to the sector for full transparency going forward.

⁴⁵ Royal Commission into violence, abuse, neglect, and exploitation of people with disability. Public hearing report 5: experiences of people with disability during the ongoing COVID-19 pandemic, 2020.

5.3 Practice standards specified for pandemics, that have been in place since November 2021, for NDIS providers, will guide responses during health emergencies

The NDIS Quality and Safeguards Commission reviewed the NDIS Practice Standards and developed a new NDIS Practice Standard and Quality Indicators for Emergency and Disaster Management, which commenced on 15 November 2021.⁴⁶ The new Practice Standard aims to strengthen guidance for providers on complying with their obligations to ensure the health, wellbeing and safety of participants during COVID-19 and future emergencies or disasters. The quality indicators for existing standards have also been amended to ensure they are relevant to emergency and disaster management.

One Committee member suggested including personalised emergency response plans at the front of participants' NDIS plans as another way to ensure that participants' emergency response needs are taken seriously.

5.4 Ensuring e-learning methods in schools are accompanied with appropriate support will improve accessibility for children with disability

In states and territories, education departments were involved in the planning and delivery of responses to COVID-19. During the pandemic and during public health lockdowns, schools introduced remote e-learning methods for teaching (replacing in-person classes) to limit the spread of the virus. For example, during the Victorian COVID-19 outbreak, most prep to year 10 students began remote e-learning in late-July, with some students (for example, those in rural and regional schools) gradually returning to onsite learning from early October.⁴⁷ In other states and territories that went into lockdown (due to stay-at-home orders), schools often transitioned to online learning, with some jurisdictions keeping schools open for onsite attendance if students required it.

Some Committee members raised that while e-learning largely helped limit the spread of COVID-19, it presented challenges and lacked accommodations for some children with disability who did not have adequate supports in place. Therefore, some children were not able to access education during this time. A carer reported that schools did not always ensure children with disability and their families were supported to transition to online learning at home. For example, their son was not able to access the platforms because there were no accessibility features to accommodate his disability.

"School systems did not tailor responses to kids with disability ... they left a lot of kids behind. [There was] limited access to school services, [some kids] could not do at-home schooling because they are deaf and there was no accommodation ... Don't want to see kids more segregated due to COVID in special schools. Many kids with disability attend mainstream schools."

— Committee member

People with lived experience also reported that when schools re-opened, there was a lack of risk management planning for children with disability who may be at higher risk of COVID-19 compared with children more generally, and risks that children with disability become excluded. People with lived experience who were interviewed stated that the public messaging that COVID-19 symptoms are mostly mild for children was not helpful when trying to communicate the risks of COVID-19 for young people with disability.

⁴⁶ NDIS Quality and Safeguards Commission, Changes to the National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018 and National Disability Insurance Scheme (Quality Indicators) Guidelines 2018, 2022.

⁴⁷ Wright, A. Primary and secondary school closures in Victoria due to COVID-19: Chronology, Parliament of Victoria, 2021.

RECOMMENDATION 13:

State and territory education departments should ensure that the diverse needs of children with disability are recognised, understood, and planned for in the current COVID-19 health response, as well as future responses introduced by education departments for other health emergencies. This involves ensuring e-learning methods are appropriate for children with disability, and to provide additional support and/or alternative methods where required; and it involves ensuring schools have in place risk management plans for infection control.

5.5 Training police in disability inclusion practices will enable more informed enforcement of public health measures

Federal, state and territory police were responsible for enforcing public health measures introduced by governments. A few Committee members reported instances where state and territory governments ensured police understood disability inclusion well. For example, one Committee member noted that police in one jurisdiction were provided training to ask for and accept letters from people with disability that outlined allowances to travel to their support programs.

"... [in one jurisdiction], the State Department of Health was getting people with disability involved with good consultation with the police. People with disabilities sometimes got pulled over on the way to programs and had trouble communicating so they would have letters and police were made aware of that."

— Committee member

However, other Committee members stated there were instances where police could have been better briefed and/or informed about exemptions for people with disability. For example, one Committee member recalled situations where people with disability and people that work closely with people with disability were accosted by police enforcing stay-at-home orders and told to go home when they were allowed to travel. It was reported that this left people with disability frightened and confused.

RECOMMENDATION 14:

State and territory health departments should ensure that other government agencies involved in health emergency responses, such as police, are adequately briefed and trained in disability inclusion practices.

6 Stakeholder views of the preparedness and response of workforces

The following section provides insights from Committee members, state and territory government representatives and people with lived experience about the preparedness of the disability sector workforce, government responses to support the workforce, and the impacts of COVID-19 on the workforce. Those consulted reported that people working closely with people with disability were not prioritised in the provision of PPE and testing, casual workers were left unsupported, workers did not have appropriate training to operate safely in a health emergency and the sector faces workforce constraints.

Summary of key learnings:

Committee members, state and territory representatives and those with lived experience engaged through the process shared the following lessons learned about the impacts of COVID-19 for the disability workforce:

- Prioritising workers in close contact with people with disability in the provision of PPE and testing will enable better health emergency responses
- Additional support for service providers may be required where they absorb higher costs associated with responding to pandemics
- Better support for casual workers during health emergencies may help limit the spread of the virus
- Appropriate training for workers to operate safely in a health emergency environment will enable better responses
- Addressing workforce constraints in the sector will enable better health emergency responses, including ensuring there is sufficient surge capacity.

6.1 Prioritising workers in close contact with people with disability in the provision of PPE and testing will enable better health emergency responses

During the first phase of the pandemic, Committee members and service providers reported that some parts of the disability sector workforce (which is comprised of a diverse range of occupation groups, such as allied health professionals and disability support workers) were left unsupported by the Australian Government. This was particularly the case for occupational groups that were not classified as 'essential services providers' or 'essential workers' by state and territory health departments. For example, a Committee member recalled one service provider of supported accommodation services having to spend about \$100,000 for the right PPE for their staff to use when providing care. Another Committee member stated that in cases where service providers were able to access PPE and COVID-19 testing equipment, such as RATs from government agencies, the rollout was slow. In addition to costs associated with buying PPE, it was also reported by a service provider that costs to transport PPE are large. One provider noted that it 'cost a few thousand dollars just to get PPE delivered the next day'.

"PPE needs to be available. Disability workers need to be classified as an essential service provider... [they] could not get [access to] PPE stockpiles due to a lack of access [for 'non-essential'] service providers."

— Committee member

"[It] took a long time to get access to services/equipment... [access to PPE] should be free. [Providers] should not have to be in the NDIS to get them. There are people outside the NDIS. And then there's the issue that at some point they stop helping."

— Committee member

A Committee member also reported that access to PPE and COVID-19 tests were provided for free to registered NDIS providers, but there are many service providers that operate beyond the NDIS. It was also reported that this support is temporary, and there are no formal policies in place regarding the use of PPE and RATs for registered NDIS providers including supported accommodation services. The NDIA has incorporated PPE costs incurred by providers into the Disability Support Workers Cost Model from 1 July 2022.⁴⁸ Several service providers reported that they are struggling financially.

Committee members noted that people working closely with those with disability need to be prioritised in the provision of PPE and testing to ensure supports and services can continue to be provided to people safely and to limit the spread of the virus.

RECOMMENDATION 15:

The Australian Government and state and territory governments should ensure that the disability sector workforce (which is comprised of a diverse range of occupation groups, such as allied health professionals and disability support workers) has access to PPE, COVID testing, and infection control/prevention knowledge and training to enhance the safety of their practice.

6.2 Additional support for service providers may be required where they absorb higher costs associated with responding to pandemics

Service providers reported that additional costs were incurred as they responded to different and dynamic care environments during COVID-19. For example, it was reported that early on in the pandemic, organisations had to dedicate significant staff time and resources to locate and understand the health advice and information that may affect their operations. This was reported to be due to the information related to the disability sector being insufficient in the initial phase.

This was made even more difficult, time-consuming, and costly when service providers operated in multiple states and/or territories, with different health advice and public health orders. These costs were reported to be substantial for smaller groups and individual independent providers with limited resources.

"The access to information was a problem. There wasn't enough access to the information. Sometimes you would hear information from the TV before from the government. At first all the information was [for] the aged care sector and not disability. We had meetings with the Exec in all different areas and tried to make sure we were covering all areas and had the right resources. That does not get covered financially, which can be very difficult."

— Service provider

In these situations, additional support for service providers may be required to ensure they are able to continue to provide support and services to people with disability. While the NDIA had provided one-off payments to registered NDIS providers in 2020, Committee members noted this needed to be repaid in the future. The NDIA has also committed to making a one-off payment to eligible registered NDIS

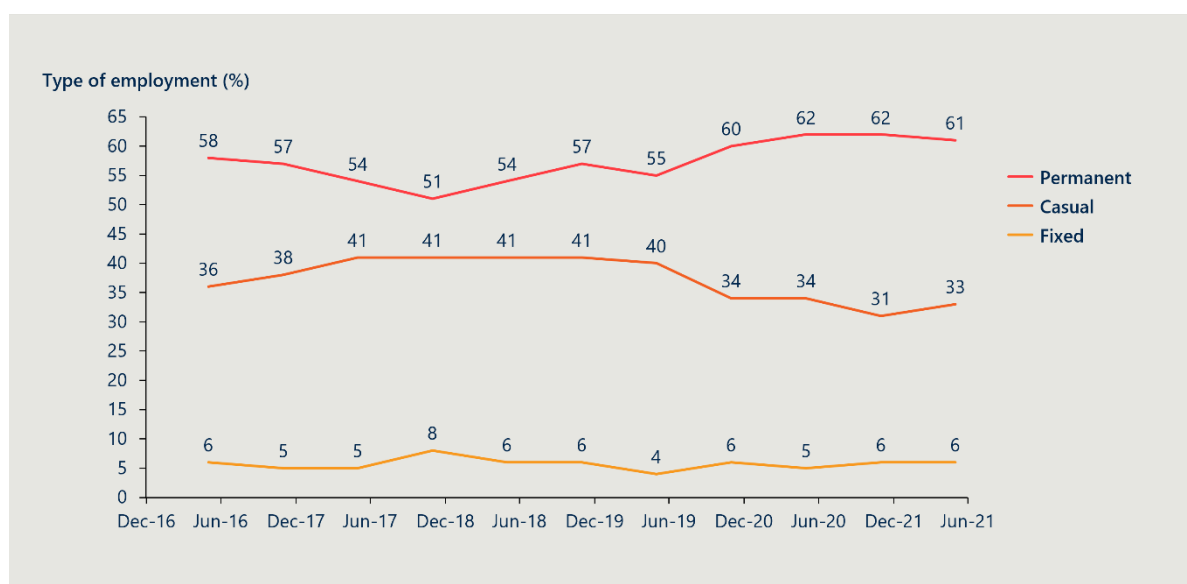
⁴⁸ NDIS, For providers – coronavirus (COVID-19), 2022. Available from: <https://www.ndis.gov.au/coronavirus/providers-coronavirus-covid-19>

providers this financial year to recognise the costs of keep NDIS participants safe during COVID-19 as part of the 2021-22 Annual Pricing Review.⁴⁹

6.3 Better support for casual workers during health emergencies may help limit the spread of the virus

A significant component of the disability sector workforce is made up of casual employees. The most recent National Disability Service Annual Market Survey of disability service providers found that in June 2021, 33 per cent of the workforce had casual employment across Australia (see Figure 3).

Figure 3 | Disability sector workforce, by type of employment⁵⁰



Several Committee members reported that casual employees were inadequately supported during COVID-19, despite them accounting for a significant proportion of the workforce. This included a lack of temporary financial support provided resulting in the workforce continuing to work, even if they were sick, to maintain their income.

Committee members felt this put people with disability at a higher risk of contracting communicable diseases, including COVID-19.

"Disability workers/companies need to be supported better. There was a lack of financial support, loans were provided by the NDIA that they then had to pay back. The workforce is casual and would come to work sick because they need the money."

— Committee member

6.4 Appropriate training for workers to operate safely in a health emergency environment will enable better responses

The disability sector workforce is comprised of a diverse range of occupational groups. This includes various allied health professionals (for example, occupational therapists and psychologists), disability support workers, and support coordinators.⁵¹

⁴⁹ NDIA, 2022-23 Pricing Announcement – One-off payment to registered service providers, 2022.

⁵⁰ National Disability Services, State of the Disability Sector, 2021.

⁵¹ National Disability Services, State of the Disability Sector, 2021.

Committee members and state and territory government representatives noted that workers in the disability sector often have various skills, knowledge and training due to the diverse occupational groups in the sector. One Committee member reported concerns that some parts of the workforce lacked appropriate training to operate in a health emergency environment. They identified one survey of workers in close contact with people with disability during COVID-19, which found that 53 per cent of workers were provided with support with tasks that require close personal contact and 23 per cent had not received any COVID-19 infection control training.⁵² Of the 77 per cent of those who did receive training, 48 per cent reported desiring additional training.⁵³

It was discussed that while workers are trained and able to provide effective support to people with disability, they were not always trained to recognise and manage risks to a person's health and connect people with disability to appropriate health care and services.

"[There was] variation in responses of disability service providers, individual support was confused with how to provide care and manage risks. The level of support is variable and there are discrepancies. This resulted in issues with access to health care, mental health, vaccinations... Feels like people providing care to people with disability can have low health literacy. [They are] good at supporting the person, but do not with the [health-related] skills and knowledge."

— Committee member

There was consensus from stakeholders that workers in close contact with people with disability need to have appropriate training to operate safely in a health emergency environment. Without this training, workers can place people with disability at higher risk of COVID-19 exposure or infection. The new and amended NDIS Practice Standards and Quality Indicators (in November 2021) have further defined the provider obligations for workforce training including in emergency and disaster situations.⁵⁴ They also outline the provider's obligations in the use of PPE and infection control.⁵⁵ The NDIS website now offers accessible e-learning and resources for providers on these topics.

6.5 Addressing workforce constraints in the sector will enable better health emergency responses, including ensuring there is sufficient surge capacity

Several Committee members and state and territory government representatives noted that during the COVID-19 pandemic, the disability sector workforce was unable to scale up using surge capacity workers to address higher needs and step in for furloughed workers. Committee members and state and territory government representatives also noted that workforce shortages were a problem before COVID-19, and that the pandemic had exacerbated these pressures. In particular, the isolation requirements introduced to slow down the spread of COVID-19, led to workers not being able to attend work for up to 14-days. A state/territory government representative felt that preparation for workforce constraints was not completed in planning for the pandemic. However, it has been reported that due to the issues experienced during the pandemic, service providers are now putting plans in place.

The Committee identified COVID-19 pandemic event visas for support workers as an important initiative that has helped (and continues to help) sustain the disability workforce. These visas enable support workers on expiring temporary visas to stay in Australia and work in key sectors like the disability sector.⁵⁶

⁵² Kavanagh A, Dimov S, Shields M, McAllister A, Dickinson H & Sully A. Disability Support Workers: The Forgotten Workforce in COVID-19 - Research Report. Melbourne: The University of Melbourne, 2020.

⁵³ Ibid.

⁵⁴ NDIS Quality and Safeguards Commission, Changes to the National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018 and National Disability Insurance Scheme (Quality Indicators) Guidelines 2018, 2022.

⁵⁵ Ibid.

⁵⁶ Australian Government Department of Home Affairs 2022, *Australian Government endorsed events (COVID-19 Pandemic event)*, accessed 16 November 2022, <<https://immi.homeaffairs.gov.au/visas/getting-a-visa/visa-listing/temporary-activity-408/australian-government-endorsed-events-covid-19>>.

Going forward, Committee members and state and territory government representatives expect the disability sector workforce to face continued workforce constraints. This is both in terms of workforce shortages, but also ensuring the right capabilities and training. While this is recognised, a common theme was that there remains a lack of strategy and planning to address this by all governments.

"COVID-19 has a massive impact on workforce because of isolation needs. There are still workforce shortages to support people with disability – before COVID-19 it was a problem, but COVID-19 has exacerbated it. It is across aged care too. States and territories are responsible for training... absolutely need a surge capacity that's not a panel of agencies who can source staff, or collating from service providers. You also need a clinical responder role – that needs to be boots on ground. This was lacking. Need all of that to be able to be called on in short notice."

— State/territory government representative

State and territory government representatives reported that workforce constraints were more profound in jurisdictions with smaller populations, and more geographically dispersed populations.

The new and amended NDIS Practice Standards and Quality Indicators from November 2021 include provider obligations for workforce planning to maintain continuity of support for participants in emergency and disaster situations.⁵⁷

RECOMMENDATION 16:

The Australian Government and states and territory governments should ensure that the proper investment, safety guidelines, training, procedures, and workforce management and planning are in place to support, sustain and expand the disability sector workforce. This includes ensuring that support workers on expiring temporary visas can stay in Australia to sustain the disability workforce in the event of a health emergency through measures like the COVID-19 pandemic event visas.

⁵⁷ NDIS Quality and Safeguards Commission, Changes to the National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018 and National Disability Insurance Scheme (Quality Indicators) Guidelines 2018, 2022.

Summary | Key learnings of Committee members, state and territory representatives and people with lived experience, and corresponding recommendations

Impact of COVID-19 for people with disability

KEY LEARNINGS

- People with disability are a diverse group and every COVID-19 experience has been different
- For many people with disability, the impact of COVID-19 has been far more significant than for people without disability
- People with disability are at high risk of COVID-19 infection and adverse outcomes
- Vaccination rates for certain people with disability remain low
- The impacts of COVID-19 and the associated physical isolation for people with disability are ongoing
- Improved data availability and linkage will enable a better understanding of the whole-of-life or longer-term impacts of COVID-19 for people with disability.

Health system responses to COVID-19 for people with disability

KEY LEARNINGS

- Systemic efforts to engage people with lived experience early on to design health responses will help ensure responses are appropriately informed from the start
- Prioritising people with disability in initial health emergency responses will help ensure that they do not feel 'left behind' like they felt during parts of the COVID-19 response
- Communication of health advice to people with disability that is tailored and through the right channels will help it reach the right target groups quickly
- Communication of health advice to people with disability that is in an appropriate format will help ensure it is effectively accessed and understood
- Community-informed responses to engaging and communicating with people with disability will help enable more effective responses and better dissemination of information
- Addressing data gaps will support more targeted rollouts of vaccines and outreach for people with disability
- Continued progress towards better data capture on people with disability will enable more informed health responses moving forward
- Where good data was available on vaccinations, this was effective in guiding targeted outreach efforts
- Improved coordination between health and disability government agencies at the Commonwealth, state and territory levels will enable better health emergency responses

RECOMMENDATION 1

Recognising that the COVID-19 pandemic is ongoing, the Committee should continue for the duration of the pandemic to support genuine stakeholder engagement, advise governments, and ensure people with lived experience are at the centre of future decision-making.

Beyond the pandemic, the Department of Health and Aged Care should undertake a review of the Committee, and other existing disability advisory structures in place, to determine if there is a need for the Committee to continue or if existing advisory structures are sufficient. If it is determined that the Committee should continue, it should be determined whether it should be a continuation of the current Committee, an altered version of the current Committee, or if it is merged with another group.

Any advisory structure in place beyond the pandemic needs to have broad representation of people with lived experience, experts, and other key stakeholders.

	However, membership should be limited to ensure inclusion is balanced with efficiency.
RECOMMENDATION 2	<p>The Department of Health and Aged Care and state and territory health departments should jointly commit to the development of a comprehensive strategy that would include an immediate needs assessment for people with disability during health emergencies, such as pandemics. For people with disability identified as a high-risk group, with high healthcare needs, the strategy should:</p> <ul style="list-style-type: none"> • categorise them as high risk and commit to prioritisation of their health needs in the response • explicitly call out what is required and what supports are available for this group in health directives and communications. <p>The Australian, state and territory governments should execute this strategy to ensure the health and social needs of people of disability are addressed in current and future responses to health emergencies.</p>
RECOMMENDATION 3	<p>The Australian Government and state and territory governments should continue to fund and deliver policies and programs to increase the vaccination rates for people with disability. This requires emphasis on the ongoing nature of the COVID-19 pandemic, targeted outreach to families and/or carers who help make health care decisions for children and people with disability, and accessible information and a range of options for vaccination supports including low sensory environment, sedation and vaccination clinics. Additionally, the Australian Government should continue to prioritise access to vaccination and infection control/prevention knowledge and training for people with disability, their families and carers, and workers in close contact with people with disability.</p>
RECOMMENDATION 4	<p>The Australian, state and territory health departments, in partnership with the Committee, should develop well-informed communication plans and strategies to ensure health advice reaches people with disability quickly during future health emergencies. Health departments should:</p> <ul style="list-style-type: none"> • lead the messaging on health advice but engage with partners who work in and/or understand the disability sector (for example, peak bodies, the NDIA and DSS) to establish communication plans to distribute health advice • document and maintain established partnerships, networks and communication channels (including those developed during COVID-19) for the duration of COVID-19 and beyond for ongoing communications and for when other health emergencies occur.
RECOMMENDATION 5	<p>The Australian, state and territory health departments, in partnership with the Committee, should ensure all communications targeted towards people with disability are in formats that people with disability want to and can engage with. All communications related to COVID-19 and future health emergencies must be available in multiple formats, including Easy Read and be available at the same time as general advice.</p>
RECOMMENDATION 6	<p>The Australian Government and state and territory governments should ensure existing community networks and relationships are documented and leveraged to support responses to health emergencies. Use of existing community resources and networks is a useful lever to communicate with people who may be difficult to reach, to spread information, support health responses and design adequate supports to address their needs.</p>
RECOMMENDATION 7	<p>The Australian Government and state and territory governments should continue to invest in improving data collection and linkage that inform policies, programs and services that affect people with disability and supports a better understanding of the effect of COVID-19 on people with disability, including ongoing effects such as long COVID. This data should be shared between the Commonwealth, state and territory governments, and where possible, with people with disability; and it should be updated frequently enough to support informed decision making.</p>

RECOMMENDATION 8	The Australian Government and state and territory governments should develop and agree on governance arrangements for health responses for people with disability during health emergencies. While health agencies are responsible for leading the health response, there should be governance structures in place that identify supporting agencies and clarify their role in supporting the health response. For people with disability, this should include the Australian Department of Social Services, NDIA, NDIS Quality and Safeguards Commission (at the Commonwealth level), and respective human services departments (at the state and territory level).
Health service and program responses to the COVID-19 pandemic	
KEY LEARNINGS	<ul style="list-style-type: none"> • In-reach vaccination and health service provision will enable more accessible services for people with disability • Providing people with disability with options to access virtual and telehealth services will support more accessible health care provision • Health liaison roles and community-based programs will enable better communication and reach with people with disability • Improvements to existing models of health care can enable more accessible and effective health care for people with disability
RECOMMENDATION 9	The Department of Health and Aged Care should maintain ongoing availability of telehealth services for people with a disability, particularly those who may face access barriers to in-person health care. Additional supports should be put in place to enable people with disability to access and use telehealth appropriately.
RECOMMENDATION 10	The Australian Government and state and territory governments should work together to ensure that liaison roles and community level responses are well supported, empowered, and equipped for future health emergencies. The governments should develop clear guidelines for liaison roles and responsibilities and provide them the tools they need to perform effective community outreach and interventions.
CONSIDERATION 1	<p>The Australian, state and territory health departments should undertake their own reviews of current health service models to understand existing barriers and challenges for people with disability in accessing and receiving health care that meet their needs, as well as the underlying drivers of this inequality, as part of future health emergency responses. Departments should also review and consider good practice examples of health care models that:</p> <ul style="list-style-type: none"> • support people with disability and their families and carers to access appropriate health care • support health care teams and hospitals to provide safer, more inclusive health care to people with disability • assist people with disability in contact with health care services access other services they may need • continue in-home testing and in-reach vaccination programs, including for COVID-19 • support decision making for people with disability and their families and carers, including in situations where there is a guardian who is responsible for decision making.
The role of sectors outside of health	
KEY LEARNINGS	<ul style="list-style-type: none"> • Temporary support measures and more flexible support for people with disability, through the NDIS, will enable more appropriate responses to health emergencies • Improved understanding, communication and coordination of the roles and interface between the NDIS Quality and Safeguards Commission and Department of Health and Aged Care during health emergencies will enable better and more efficient responses

	<ul style="list-style-type: none"> Practice standards specified for pandemics, that have been in place since November 2021, for NDIS providers, will guide responses during health emergencies Ensuring e-learning methods in schools are accompanied with appropriate support will improve accessibility for children with disability Training police in disability inclusion practices will enable more informed enforcement of public health measures
RECOMMENDATION 11	The NDIA should ensure NDIS plans are flexible enough to support NDIS participants during health emergencies, such as the COVID-19 pandemic. In these situations, participants may require increased financial support for additional services, such as a temporary support worker in cases where their family care giver becomes ill.
RECOMMENDATION 12	The NDIS Quality and Safeguards Commission, in consultation with the Department of Health and Aged Care, should improve understanding, communication and coordination of their roles and responsibilities during health emergencies and obligations of providers to provide high-quality NDIS supports consistent with their obligations under the <i>NDIS Act 2013</i> (Cth). This should include clarifying responsibilities for educating and building capability of providers to respond safely during health emergencies, and in ensuring compliance with health requirements and mandates. Clarified roles and responsibilities should be effectively communicated to the sector for full transparency going forward.
RECOMMENDATION 13	State and territory education departments should ensure that the diverse needs of children with disability are recognised, understood, and planned for in the current COVID-19 health response, as well as future responses introduced by education departments for other health emergencies. This involves ensuring e-learning methods are appropriate for children with disability, and to provide additional support and/or alternative methods where required; and it involves ensuring schools have in place risk management plans for infection control.
RECOMMENDATION 14	State and territory health departments should ensure that other government agencies involved in health emergency responses, such as police, are adequately briefed and trained in disability inclusion practices.
The preparedness and response of workforces	
KEY LEARNINGS	<ul style="list-style-type: none"> Prioritising workers in close contact with people with disability in the provision of PPE and testing will enable better health emergency responses Additional support for service providers may be required where they absorb higher costs associated with responding to pandemics Better support for casual workers during health emergencies may help limit the spread of the virus Appropriate training for workers to operate safely in a health emergency environment will enable better responses Addressing workforce constraints in the sector will enable better health emergency responses, including ensuring there is sufficient surge capacity
RECOMMENDATION 15	The Australian Government and state and territory governments should ensure that the disability sector workforce (which is comprised of a diverse range of occupation groups, such as allied health professionals and disability support workers) has access to PPE, COVID testing, and infection control/prevention knowledge and training to enhance the safety of their practice.
RECOMMENDATION 16	The Australian Government and states and territory governments should ensure that the proper investment, safety guidelines, training, procedures, and workforce management and planning are in place to support, sustain and expand the disability sector workforce. This includes ensuring that support workers on expiring temporary visas can stay in Australia to sustain the disability workforce in the event of a health emergency through measures like the COVID-19 pandemic event visas.

Appendix A | Stakeholder consultations

Nous would like to thank all stakeholders for dedicating their time to provide meaningful input that helped shape the Lessons Learned report. A list of organisations involved in the process is included below. There was also additional engagement with 19 people with lived experience including people with disability, carers and workers.

Verbal interview submissions	Written submissions
Australian Association of Psychologists Inc	ACT Government
Australian Association of Developmental Disability Medicine	First Peoples Disability Network Australia (Royal Commission Submission)
Allied Health Professions Australia	Representatives from Queensland Government
Australian Human Rights Commission	Indigenous Allied Health Australia (Royal Commission Submission)
Council for Intellectual Disability and Inclusion Australia	Tasmanian Government
Department of Developmental Disability Psychiatry, University of New South Wales	President, Royal Australian College of Physicians
Disability and Health Unit, University of Melbourne	South Australian Government
Down Syndrome Australia	Western Australia Government
Get Skilled Access	
Life Without Barriers	
Representatives from the NDIS Quality and Safeguards Commission	
Representatives from the New South Wales Government	
Northcott Innovation	
Representatives from the Northern Territory Government	
Multicap	
Representatives from the National Disability Insurance Agency	
Representatives from the Australian Department of Social Services	
Representatives from the Australian Department of Health and Aged Care	
Victorian Disability Advisory Council	
Representatives from the Victorian Government	