Public Hearing Report

Public hearing 5
Experiences of people with disability during the ongoing COVID-19 pandemic

Sydney
18 – 21 August 2020
26 November 2020

His Excellency General the Honourable David Hurley AC DSC (Retd)
Governor-General of the Commonwealth of Australia
Government House
CANBERRA ACT 2600

Your Excellency,

From 18 to 21 August 2020, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability held a hearing which inquired into the experiences of people with disability during the COVID-19 pandemic.

We now submit to you the Commissioners’ Report on Public hearing 5: Experiences of people with disability during the ongoing COVID-19 Pandemic.

We are also submitting this report to their Excellencies the Governors of New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia.

Yours sincerely,

The Honourable Ronald Sackville AO QC

Ms Barbara Bennett PSM

Dr Rhonda Louise Galbally AC
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Findings and recommendations

This section of the report on Public hearing 5 (Experiences of people with disability during the ongoing COVID-19 pandemic) records the findings and recommendations made by the Commissioners. The findings and recommendations are grouped under headings that correspond to the major headings in the body of the report.

Introduction and overview

Recommendation

Recommendation 1:
The Australian Government should consider the findings and recommendations in this report as a matter of urgency.

The early response

Findings

- During the early stages of the COVID-19 pandemic no agency of the Australian Government, including the Department of Health and other agencies responsible for disability policy, made any significant effort to consult with people with disability or their representative organisations. Even allowing for the novel challenges presented by the coronavirus this was a serious failure.

- The failure to consult during the critical early period contributed to the Australian Government neglecting to develop policies specifically addressing the needs of people with disability and the challenges confronting them in an emergency unprecedented in modern times.

- The failure of the Australian Government to consult people with disability and the related failure to develop a plan specifically addressing the needs of and challenges faced by people with disability produced serious adverse consequences for many people with disability. These consequences varied depending on local circumstances but they included:
- extreme stress and anxiety related to fear of contracting coronavirus because of exposure to different support staff and the absence of adequate PPE for support staff and people with disability themselves

- the sudden loss of essential support services in the absence of programs designed to ensure continuity of such services for people with disability, especially those living in closed environments

- impaired health and wellbeing due to an inability for prolonged periods to access essential supplies such as food and medications

- significant distress, particularly among people with cognitive disability, due to the lack of clear and consistent information about the pandemic and the measures taken to control it

- threats to mental health due to a belief by some people with disability, including those in disability accommodation settings, that they had been forgotten and ignored, which was exacerbated by enforced isolation from family, friends and social networks and the absence of strategies to ameliorate the consequences of isolation.

- In the absence of comprehensive data about the rates of COVID-19 infection and death among people with disability we are unable to determine whether any of the infections or deaths could have been prevented with better planning for the disability sector. But the evidence does not allow us to reject the hypothesis that better planning may well have done so.
Recommendations

**Recommendation 2:**

The Australian Government should explicitly commit to ensuring that all agencies responsible for planning and implementing responses to the COVID-19 pandemic and any future emergencies establish and implement formal mechanisms for consulting with and involving people with disability and disability representative organisations in planning and giving effect to the responses.

**Recommendation 3:**

The Australian Government should provide the funding and support required for disability representative organisations and, where appropriate, individual people with disability to participate in consultations with Australian Government agencies and advisory bodies responsible for planning and implementing policies and programs to safeguard the health, safety and wellbeing of people with disability during the COVID-19 pandemic and any future national emergency.

**Recommendation 4:**

The Australian Government should identify any gaps in current consultation processes employed by departments and agencies which have responsibility for the safety, health and wellbeing of people with disability during the COVID-19 pandemic or other national emergencies. This process should include but not be limited to the Australian Government Department of Health, the National Disability Insurance Agency and the NDIS Quality and Safeguards Commission.
The later responses

Finding

Although the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability or a similar body including representation of disability advocacy groups and individual people with disability should have been created before 2 April 2020, its establishment was a positive development. The Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability has played a useful role since its establishment in informing the responses of the Australian Government to protecting the safety, health and wellbeing of people with disability during the pandemic.

Recommendations

Recommendation 5:

The Australian Government should ensure that the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability continues to function for the duration for the COVID-19 pandemic and the recovery period and that it receives sufficient funding and support to fully discharge its responsibilities.

Recommendation 6:

The Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability, or a similar body, including significant representation of disability advocacy groups and people with disability, should remain in place after the pandemic has come to an end and the recovery is complete. While such a body might meet only sporadically during ‘normal’ times, it should be capable of reactivation at very short notice in the event of a fresh emergency that might affect the safety, health and wellbeing of people with disability.
First Nations people with disability

Recommendations

Recommendation 7:
The terms of reference of the Aboriginal and Torres Strait Islander Advisory Group on COVID-19 should be amended to state expressly that its work is to include providing advice with respect to First Nations people with disability.

Recommendation 8:
The membership of the Aboriginal and Torres Strait Islander Advisory Group on COVID-19 should be extended to include at least one member who represents the interests of First Nations people with disability.

Guidelines for outbreaks

Finding

We find that the Australian Government failed to give clear guidance to service providers about the differences between residential aged care settings and disability accommodation settings in relation to infection control and outbreak management.

Recommendation

Recommendation 9:
The Australian Government Department of Health in consultation with the NDIS Quality and Safeguards Commission and the National Disability Insurance Agency should prepare comprehensive guidelines specifically addressing the prevention, control and public health management of COVID-19 outbreaks in disability accommodation settings, taking into account the differences between residential aged care settings and disability accommodation settings.
Department of Health

Finding

The evidence strongly supports the view that a single unit should be responsible for planning to protect and improve the health, safety and wellbeing of people with disability in emergencies such as the COVID-19 pandemic and more generally. This applies to planning for health emergencies, pandemics and communicable diseases. We are not able to conclude with certainty that the presence of a single unit of this kind within the Australian Government Department of Health at the outset of the COVID-19 pandemic would have produced better outcomes for people with disability. However, we find that it is very likely that had such a unit been in place the Australian Government Department of Health would have consulted with disability representative organisations and individual people with disability earlier than in fact occurred. Had these consultations taken place they may well have produced more effective plans for the protection of the health, safety and wellbeing of people with disability, particularly in the early stages of the pandemic. This was an opportunity lost.

Recommendation

Recommendation 10:

The Australian Government Department of Health should ensure that an appropriately resourced unit or team has specific responsibility for developing plans and programs to protect the health and wellbeing of people with disability, including during emergencies such as the COVID-19 pandemic. This unit should be responsible for coordinating health and disability responses to emergencies such as the COVID-19 pandemic. The unit should operate in addition to the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability and should work closely with that Committee.
Testing and screening for people with disability

Findings

- There appears to be no documentation demonstrating that any agency or department of the Australian Government responsible for disability policy and administration gave specific consideration prior to the release of the Management and Operational Plan for People with Disability on 17 April 2020 to putting in place arrangements to ensure as far as possible that all people with disability would have access to testing or screening for COVID-19.
- We infer from the evidence that failure to introduce measures to make COVID-19 testing accessible to all people with disability caused significant distress to people who were unable to access testing for COVID-19 during the early stages of the pandemic.
- The Management and Operational Plan for People with Disability was a welcome development because it identified changes necessary to ensure that all people with disability have access to testing for COVID-19. However, the proposed changes had not been fully implemented by the date of the hearing.

Recommendation

Recommendation 11:
The Australian Government should implement fully the testing and screening arrangements identified in the Management and Operational Plan for People with Disability without delay.
Independent advocacy

Findings

- The regular funding provided to disability representative organisations by the Australian Government was insufficient to enable them to cope with the substantially increased demand for systemic and individual advocacy from the outset of the COVID-19 pandemic. Had additional funding to disability representative organisations been provided, they would have been helped to meet the needs of many more people with disability and would have been assisted to make more substantial and earlier contributions to the planning of responses.

- It is virtually inevitable that substantially increased demand for the individual advocacy services of disability representative organisations will be a feature of any resurgence of the pandemic or any future emergency affecting the entire Australian community or significant sections of it.

Recommendations

**Recommendation 12:**
The Australian Government should immediately commit to providing supplementary funding to disability representative organisations for individual advocacy should there be a significant resurgence of COVID-19 in Australia.

**Recommendation 13:**
The Australian Government should commit to providing supplementary funding to disability representative organisations for individual and systemic advocacy whenever a new pandemic or major emergency (such as a natural disaster) occurs. The commitment should include establishing an emergency fund that can be drawn upon as soon as the need arises.
Lack of data

Findings

- The Australian Government Department of Health has not collected data about how many people with disability have contracted COVID-19 since the onset of the pandemic in January 2020.
- Data about infections and deaths in disability accommodation under the ‘other residential care facility setting’, which was first collected at a late stage of the pandemic, should have been disseminated, but has not been published.
- Because of the deficiencies in the collection and dissemination of data, it is not possible to obtain a complete or accurate picture of the infection and mortality rates from COVID-19 for people with disability throughout Australia.
- The failure to collect and disseminate national data on the rates of infection and death from COVID-19 for people with disability is inconsistent with Australia’s obligations under article 31 of the United Nations Convention on the Rights of Persons with Disabilities.

Recommendations

**Recommendation 14:**

The Australian Government should immediately introduce measures to ensure that it complies with its obligations under article 31 of the United Nations Convention on the Rights of Persons with Disabilities. For this purpose:

14.1 The Australian Government should ensure that the proposed COVID-19 registry disaggregates data by disability status and by reference to people in ‘residential disability care facilities’.

14.2 The Australian Government Department of Health should publish statistics at least weekly on the number of confirmed active COVID-19 cases, deaths and recovered cases in Australia for each state and territory for people living in ‘residential disability care facilities’.
14.3 The Australian Government Department of Health in co-ordination with the NDIS Quality and Safeguards Commission should publish statistics at least weekly on the number of confirmed active COVID-19 cases, deaths and recovered cases among National Disability Insurance Scheme participants in Australia and in each state and territory.

NDIS Quality and Safeguards Commission

Findings

- From the onset of the COVID-19 pandemic the NDIS Quality and Safeguards Commission adhered to its policy of placing responsibility on registered service providers to determine the risk factors affecting National Disability Insurance Scheme participants and to ensure their safety, health and wellbeing. The NDIS Quality and Safeguards Commission followed this course notwithstanding that circumstances had changed radically and the risks to National Disability Insurance Scheme participants had increased substantially.

- The *National Disability Insurance Scheme Act 2013* (Cth) did not preclude the NDIS Quality and Safeguards Commission from adopting a more active approach during the COVID-19 pandemic. If the NDIS Quality and Safeguards Commission believed that a more active role was outside its statutory functions, that belief was based on an unduly narrow interpretation of the legislation.

- The NDIS Quality and Safeguards Commission did not take specific steps to intensify active oversight of National Disability Insurance Scheme participants living in closed residential settings in response to the isolation they experienced due to the COVID-19 pandemic.

- While we are unable to conclude on the evidence that a more active approach would have prevented infections and deaths among National Disability Insurance Scheme participants and
support staff, the decision to maintain existing policies and practices represented a lost opportunity to protect and safeguard the safety, health and wellbeing of National Disability Insurance Scheme participants.

Recommendations

**Recommendation 15:**
The NDIS Quality and Safeguards Commissioner should review the National Disability Insurance Scheme Practice Standards and National Disability Insurance Scheme Quality Indicators to ensure that they are appropriate for pandemics and other emergencies. The review should be informed by the views of people with expertise in public health emergencies including pandemics and outbreaks of infectious diseases.

**Recommendation 16:**
The NDIS Quality and Safeguards Commissioner’s policies, procedures and practices should reflect its powers and responsibilities to take active measures to protect and preserve the safety, health and wellbeing of National Disability Insurance Scheme participants during an emergency such as a pandemic.

Disability workforce

**Findings**
- People with disability in disability accommodation settings, especially those with co-morbidities, were exposed to a greater risk of infection than other members of the community (including other people with disability), during the early stages of the pandemic. The heightened risk was due to the extent to which service providers relied on casual disability support staff.
During the early stages of the COVID-19 pandemic the Australian Government did not provide disability support workers priority access to PPE, thereby exposing both the workers and the people with disability whom they supported to an increased risk of infection.

**Recommendations**

*Recommendation 17:*

The Australian Government in coordination with the states and territories should take all practicable steps to ensure that in the event of a resurgence of COVID-19, disability support workers have priority access to:

- PPE and
- testing for COVID-19.

*Recommendation 18:*

The Australian Government in coordination with the states and territories should set in place arrangements to ensure that in the event of a future pandemic, disability support workers have priority access to:

- PPE and
- appropriate testing procedures.

*Recommendation 19:*

The Australian Government Department of Health should evaluate the effectiveness of the online training program released on 16 March 2020, taking into account the report *Disability Support Workers: The forgotten workforce in COVID-19.*
Health care rationing

Findings

- Fortunately Australia has not had to confront a situation where COVID-19 has led to the demand for intensive care unit beds outstripping the number of beds available. Nor is there any evidence that in such a situation the Department of Health or any other health authority in Australia would have rationed intensive care unit beds in a manner that discriminated against or unfairly prejudiced people with disability.

- Nonetheless during the pandemic many people with disability have held genuine fears that health care rationing would be introduced and that if it was, people would be denied access to intensive care unit beds and other essential health services solely by the reason of their disability.

- Although the Australian and New Zealand Intensive Care Society developed guidelines that guard against health care rationing during the pandemic on the basis of disability, the Australian Government Department of Health has published no such guidelines. Had it done so, the published guidelines may have reassured those people with disability who feared the introduction of health care rationing.
Recommendations

**Recommendation 20:**

The Australian Government Department of Health should publish guidelines making it clear that access to health services during the pandemic will never be rationed by denying people with disability access to such services by reason of their disability.

**Recommendation 21:**

These guidelines should be drafted in consultation with the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability and should explicitly address access to intensive care units and to a COVID-19 vaccine, if and when one becomes available.

**Recommendation 22:**

The Australian Government Department of Health should recommend to relevant state and territory departments and agencies that they publish similar guidelines. Such statement could be formulated, for example, by the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability and endorsed by the Department of Health. It should explicitly address access to intensive care units as well as access to a COVID-19 vaccine, if and when one becomes available.
Introduction and overview

1. COVID-19 is the name of the illness that is caused by the virus SARS-CoV-2. The virus first emerged in Wuhan in China in late December 2019. It is a highly infectious virus, which can cause serious symptoms and death, particularly in older people or those with chronic conditions. It is called a ‘novel virus’ because it is a new virus, for which as yet there is no effective vaccine or treatment.

2. Australians with disability are an ‘at risk’ population during the COVID-19 pandemic because many have underlying illnesses or immunocompromised conditions and are at greater risk of infection than the general population and are more likely to experience more severe outcomes. Many people with disability, such as those with complex needs, require personal support that puts them in close contact with other people in circumstances that make it impossible to physically distance. Often, disability support workers provide support to more than one person with disability, or also support older people, increasing the chance of workers becoming infected and passing the infection on to people they support.

3. On 26 March 2020, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Royal Commission) published a Statement of Concern expressing its deep concern about the impact of the COVID-19 pandemic on people with disability. The statement recorded that the Royal Commission had been told that people with disability:

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1 Transcript, Anne Kavanagh, Public hearing 5, 20 August 2020, P-202 [19-20].
2 Transcript, Anne Kavanagh, Public hearing 5, 20 August 2020, P-202 [23-24].
3 Transcript, Anne Kavanagh, Public hearing 5, 20 August 2020, P-202 [24-25].
4 Transcript, Anne Kavanagh, Public hearing 5, 20 August 2020, P-202 [28-29].
5 Exhibit 5.75, EXP.0003.0003.0001 at 0014; Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [39].
6 Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [40].
7 Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [40].
• continue to face barriers in accessing health care, including prevention, screening and treatment for COVID-19

• are unable to access regular and vital medications and therapeutic services due to low supplies and restrictions in access

• may not have access to mental health services at a time when the need for accessible and responsive mental health is heightened

• are unable to easily access essential health supplies to keep themselves safe, such as personal protective equipment (PPE), hand sanitiser and sterilising equipment

• are worried that discrimination or unconscious bias could impact their access to critical and lifesaving health care during this crisis.8

4. In its statement, the Royal Commission expressed particular concern about the position of people with disability in closed residential settings and the impact of the COVID-19 pandemic on First Nations people with disability. It called on all Australian governments to ensure that their strategies in responding to the pandemic incorporated all necessary measures to ensure the protection and safety of people with disability.9

5. On 15 April 2020 the Royal Commission published an issues paper on emergency planning and responses. The *Emergency planning and response issues paper* identified threats to health, safety and wellbeing when people with disability are ignored or are left behind in emergencies.

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8 Exhibit 5.37, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Statement of Concern*, 26 March 2020, ASA.0001.0001.9715 at 9716.

such as the COVID-19 pandemic. The issues paper invited responses to a series of questions.

6. The Royal Commission received 72 responses, some very detailed, to the questions asked in the issues paper. In addition, many submissions to the Royal Commission (as distinct from responses to the issues paper) contended that governments in Australia had failed to take adequate measures to protect people with disability during the pandemic and gave examples of the consequences of those failures.

7. Many responses recounted the experiences of people with disability and their families during the pandemic. These included significant difficulties in accessing essential goods and services such as food, medication, education and PPE. Respondents spoke of the anxiety, isolation and neglect caused by the cancellation or disruption of essential services including disability supports and community access. There were calls for governments and service providers to consult with people with disability, their advocates and representative organisations when developing responses to the pandemic. Disability advocates and people with disability contended that proper

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consultation would ensure that policies and practices reflected the needs of people with disability,14 were culturally appropriate15 and took a ‘person-centred approach’.16

8. Concerns were also expressed about the quality and timeliness of information made available during the pandemic, including:

- delays in disseminating accessible information about the COVID-19 pandemic across an array of platforms, including in using Auslan interpreters, captioning and in publishing materials in Easy Read form17
- lack of clarity over the ‘essential’ status and continuity of disability support services18

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14 Name withheld, Submission in response to Emergency planning and response issues paper, 15 July 2020, ISS.001.00255; Queensland Advocacy Incorporated, Submission in response to Emergency planning and response issues paper, 1 June 2020, ISS.001.00199; Children and Young People with Disability Australia, Submission in response to Emergency planning and response issues paper and Education and learning issues paper, 26 July 2020, ISS.001.00293.
15 First Peoples Disability Network Australia, Submission in response to Emergency planning and response issues paper, 7 August 2020, ISS.001.00337.
16 See for example, Name withheld, Submission in response to Emergency planning and response issues paper, 23 April 2020, ISS.001.00139.
• distress and confusion caused by a barrage of constantly changing information about COVID-19 restrictions.\(^{19}\)

9. Responses explained how restrictions arising under the pandemic were adversely affecting particular groups of people with disability. Some people with cognitive disability did not understand or were not able to comply with physical distancing requirements and could even face inappropriate punishment for apparent contraventions.\(^{20}\) People dependent on close physical support for mobility and personal care or people who were visually impaired sometimes found that physical distancing was impossible.\(^{21}\)

10. In June 2020, the Royal Commission announced that it would hold a public hearing to examine the experiences of people with disability during the ongoing COVID-19 pandemic.

11. Public hearing 5: Experiences of people with disability during the ongoing COVID-19 pandemic took place from 18 to 21 August 2020 in Sydney (Public hearing 5 or hearing) before the Honourable Ronald Sackville AO QC (Chair), Ms Barbara Bennett PSM and Dr Rhonda Galbally AC (Commissioners).


\(^{21}\) Blind Citizens Australia, Submission in response to Emergency planning and response issues paper, 7 July 2020, ISS.001.00239.
Anthony Mulholland

Anthony Mulholland is a First Nations man living on his own in Western Sydney. Anthony has an intellectual disability and has an NDIS plan which includes assistance from a support worker.

Anthony said that during COVID-19 he was confused both by the news because ‘every day they were changing the rules’ and ‘by there being multiple chief medical officers.’ He said there were different messages from the Prime Minister and the Premier and he didn’t know who was in charge. Anthony said that, over time, information came more quickly, there was no consistency, and that in the end he ‘didn’t know which way to turn.’

Anthony shared his experience of isolation during the lockdown, saying:

I missed Easter with my family. I was so depressed around Easter. My mental health was bad. I had a nervous breakdown. I couldn’t see my parents over Easter. It upset me so much. I was alone. I felt so isolated. I was not coping well.

Although he could speak to his parents by phone, technology is not easy for Anthony. He said ‘[n]ot all persons with disability have smart phones and good internet.’

When he went out, Anthony saw people getting fined and he was worried about getting caught out. He said that people were staying away from him, keeping their distance and it felt like people didn’t want to talk to him. This made him feel upset and sad because he is a sociable person. This happened particularly at shopping centres, and it made him feel very nervous so he started going shopping at night. Anthony said that on one occasion when he was going grocery shopping, he was stopped and questioned by police which was ‘so scary.’

Anthony explained that it was difficult for people with disabilities to understand social distancing and comprehend what was going on. He said that people with disabilities like routine and that their ordinary routines had changed due to COVID-19, resulting in behavioural issues. For example, they were no longer able to go on train trips and this ‘made them feel upset like they’ve done something wrong and they were in trouble.’ Anthony said that people with disabilities need to be reassured that they are not going to be punished.
Preparation of the report

12. This report has been prepared by the three Commissioners who participated in Public hearing 5. Commissioners Atkinson, Mason and Ryan have read and commented on the draft of the report. Those comments have been taken into account by the Commissioners responsible for the contents of the report.

13. Commissioner McEwin very properly declared a potential conflict of interest in the subject matter of Public hearing 5 at the earliest possible time. For that reason he has played no part in the preparation of the report or in the consideration of issues arising from Public hearing 5.

The hearing

14. The principal purpose of Public hearing 5 was to examine the response of the Australian Government to the risks to the health, safety and wellbeing of people with disability during the pandemic, taking into account Australia's obligations under international law. It is important to appreciate, however, that the hearing sought not only to identify measures that the Australian Government failed to take, but also measures it did take that had a positive impact on people with disability.

15. This was the fifth public hearing of the Royal Commission.\textsuperscript{22} However, it was the first since it was forced to suspend public engagements because of restrictions imposed by governments in the interests of community safety in response to the pandemic. Public hearing 5 was conducted as a virtual hearing, with most witnesses appearing remotely. Two Commissioners were present in the Sydney hearing room, while one participated from Melbourne.

16. Counsel Assisting the Royal Commission at the hearing were Ms Kate Eastman SC and Dr Kerri Mellifont QC, instructed by the Office of the

\textsuperscript{22} The previous hearings of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability are Public hearing 1: Ceremonial opening sitting; Public hearing 2: Inclusive education in Queensland – preliminary inquiry; Public hearing 3: The experience of living in a group for people with disability; and Public hearing 4: Health care and services for people with cognitive disability.
Solicitor Assisting the Royal Commission. Counsel Assisting presented evidence from 36 witnesses during the hearing. The witnesses included people with disability, parents, siblings, support workers, advocates, experts, medical professionals, service providers and representatives of the Australian Government.

17. Four parties were granted leave to appear at the hearing: the Australian Government, the State of Victoria, and two service providers – Life Without Barriers and Aruma Services (Aruma).

18. The Chair stated at the outset of Public hearing 5 that the Commissioners participating in the hearing did not intend to wait until the release of the Royal Commission’s final report to make findings and recommendations on the issues addressed at the hearing. We took into account that the pandemic might last for a long time and might continue to affect people with disability more acutely than other groups within the community. We formed the view that the Royal Commission has a responsibility to people with disability to prepare a report on a continuing emergency as soon as practicable.

19. The evidence at Public hearing 5 addressed the profound impact of the pandemic on the health, safety and wellbeing of many people with disability. Witnesses spoke of the sudden loss of support services essential to daily life; a lack of access to basic necessities such as food and medications; and uncertainty about the prospects for survival in the face of prolonged disruptions to essential care and support.

20. Witnesses also told of other harrowing experiences, such as extreme stress and anxiety caused by potential exposure to the virus through contact with different casual support staff on a daily basis; a lack of PPE both for the person with disability and support staff; enforced isolation from family, friends and social networks; and the absence of clear, consistent and accessible information about the pandemic and the changing rules in place, particularly for people with cognitive disability. The Royal Commission also heard of increases in levels of
domestic violence, mental illness and economic hardship among people with disability.

21. The Royal Commission heard that measures designed to prevent the spread of the virus, including restrictions on visiting, limited the operation of formal oversight mechanisms (such as Community Visitor Schemes) and curtailed informal oversight provided by family, friends, supporters and advocates. The constraints on these safeguards increased the risk of violence, abuse, neglect and exploitation, particularly to people living in specialist disability accommodation.

22. A nationally representative online survey of 15,000 women highlighted the increased risk of domestic violence against women during the pandemic. The survey was conducted by the Australian Institute of Criminology and included 1,700 women with disability (11 per cent of the total number). Women with disability were more likely than other women to have experienced the onset or escalation of domestic violence during the initial stages of the pandemic.

23. From April to June 2020, Children and Young People with Disability Australia (CYDA) conducted a survey that focused on ‘the educational experiences of students with disability, before and during the pandemic’. One of the key findings of the report was that ‘72% of students with disability were more socially isolated than their classmates’. CYDA reported that students were being sent home with complicated, unmodified work and were left to try and work it out for themselves. CYDA also reported that schools’ and teachers’ low expectations of students with disability affected their experiences during the pandemic.

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23 Exhibit 5.71, CTD.9700.0001.0020. The Australian Institute of Criminology used the term ‘restrictive long term health condition’, which corresponds closely to the Australian Bureau of Statistics’ definition of disability.
24 Exhibit 5.71, CTD.9700.0001.0020 at 0045.
25 Exhibit 5.28, Statement of Mary Sayers, 12 August 2020, at [15-19], [21].
26 Transcript, Mary Sayers, Public hearing 5, 19 August 2020, P-173 [6-7].
27 Transcript, Mary Sayers, Public hearing 5, 19 August 2020, P-172 [27-30], [32-37].
Evidence was given at the hearing about the challenges faced by people with disability in accessing health services. Some people experiencing illness or health problems avoided seeking medical assistance until the symptoms worsened, leading to poorer outcomes. New signs and procedures in hospitals were not always accessible for all people with disability, especially those with sensory disabilities. Witnesses told the Royal Commission that having access to telehealth from 13 March 2020 was a welcome change as the new scheme improved access to health care.

The hearing sought to elicit information from the Australian Government as to the rates of coronavirus infection for people with disability and the number of people with disability who have died from the virus. The evidence, to which we refer in more detail later, was that no national data on either of these crucial issues was available. However, the National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission (NDIS Commission) gave evidence at the hearing that as at 13 August 2020, 76 NDIS participants and 124 disability support workers for NDIS participants had contracted COVID-19.

In his closing remarks at the hearing, the Chair identified a series of issues that might be addressed by Counsel Assisting in their written submissions. Counsel Assisting duly prepared written submissions in accordance with directions made by the Chair (Counsel Assisting’s submissions). Counsel Assisting made separate

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28 Transcript, Dr Dinesh Palipana, Public hearing 5, 20 August 2020, P-235 [20-39].
29 Exhibit 5.13, Statement of Dr Dinesh Palipana, 4 August 2020, at [30-32].
30 Exhibit 5.3, Statement of Ricky Buchanan, 4 August 2020, at [56]; Exhibit 5.18, Statement of Nicole Lee, 10 August 2020, at [24].
31 See Report, [150-159].
32 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [173].
33 Transcript, the Chair, Public hearing 5, 21 August 2020, P-411 [10]-P413 [25].
34 Submission of Counsel Assisting, Public hearing 5, 4 September 2020, DRC.9999.0019.0001.
35 Direction, OR-CTH-5-1.
supplementary submissions\textsuperscript{36} concerning the evidence given on behalf of Aruma and Life Without Barriers (supplementary submissions).

27. The Royal Commission received submissions in response to both sets of Counsel Assisting’s submissions from the Australian Government (Australian Government’s submissions).\textsuperscript{37} Aruma and Life Without Barriers also filed written submissions.\textsuperscript{38} All submissions have been taken into account in the preparation of this report.

28. Counsel Assisting’s submissions, the supplementary submissions and submissions made by parties with leave to appear were published along with this report and are available on the Royal Commission’s website.

Scope of the report

29. This report does not summarise the evidence heard over four days at Public hearing 5.\textsuperscript{39} Nor does it make factual findings in relation to the experiences of individual witnesses or members of their families. This is because the focus of the report is on the experiences of people with disability during the pandemic and the Australian Government’s responses (or failures to respond) that directly affected people with disability.

30. We recognise that Public hearing 5 did not examine the whole of the Australian Government’s responses to the COVID-19 pandemic.\textsuperscript{40} Nevertheless, the experiences of people with disability during the

\textsuperscript{36} Supplementary Submission of Counsel Assisting, Public hearing 5, 10 September 2020, DRC.9999.0019.0170.
\textsuperscript{37} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014.
\textsuperscript{38} Submission of Aruma Services, Public hearing 5, 15 September 2020, SUBM.0003.0007.0007; Submission of Life Without Barriers, Public hearing 5, 18 September 2020, SUBM.0005.0001.0002.
\textsuperscript{39} The Commissioners adopt the summary of witness evidence set out in the Submission of Counsel Assisting, Public hearing 5, 4 September 2020, DRC.9999.0019.0001 at Part 2.
\textsuperscript{40} The Commissioners acknowledge that the evidence in Public hearing 5 did not examine the whole of the Australian Government’s response to the COVID-19 pandemic. This is also recognised in the Submission of Counsel Assisting, Public hearing 5, 4 September 2020, DRC.9999.0019.0001 at [435].
pandemic reinforce the disquiet expressed by the Royal Commission in the Statement of Concern and justify us in making findings about the adequacy of the responses of the Australian Government. The evidence has also permitted us to make recommendations designed to ensure that the Australian Government protects and safeguards the health, safety and wellbeing of people with disability not only during the current pandemic but in future emergencies.

31. The experiences of people with disability underline the importance of the Australian Government, in co-operation with the states and territories, implementing measures necessary to protect and support people with disability during the pandemic and in future emergencies. At the date of publication of the report, COVID-19 appears to be largely under control throughout Australia. However, the uniform advice from infectious disease experts is that further waves of infection may occur and that an effective vaccine will not be available for a considerable period. The resurgence of the virus in so many countries demonstrates that Australia must be prepared for a further outbreak.

**Recommendation 1:**

The Australian Government should consider the findings and recommendations in this report as a matter of urgency.

**Human rights framework**

32. Australia is a party to and has ratified the United Nations *Convention on the Rights of Persons with Disabilities*41 (CRPD). Article 1 of the CRPD states that its purpose is:

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A number of other articles of the CRPD are relevant to an assessment of the Australian Government’s responses to the pandemic.

Article 4(3): consultations

33. Article 4 of the CRPD specifies ‘General obligations’ with which States Parties must comply. Article 4(3) imposes an obligation to consult people with disability in the following terms:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

34. Ms Catalina Devandas, then the United Nations Special Rapporteur on the rights of persons with disabilities, told the Royal Commission that it is important for governments to consult with and ensure the active participation of people with disability and their representative organisations at all stages of the COVID-19 responses and of the recovery. Ms Devandas expressed the view that participation is a core human rights principle and a basic condition of democratic societies.\(^42\)

Ms Rosemary Kayess, an expert who played an important role in the drafting of the CRPD, expressed similar views.\(^43\)

Article 11: situations of risk

35. For present purposes the most significant provision of the CRPD is article 11. It states that States Parties, including Australia:

shall take, in accordance with their obligations under international law, including international humanitarian law and international

\(^42\) Exhibit 5.29, Statement of Catalina Devandas Aguilar, 10 August 2020, at [40].

\(^43\) Exhibit 5.19, Statement of Rosemary Kayess, 13 August 2020, at [44-48].
human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

36. In 2013, well before the pandemic occurred, the Committee on the Rights of Persons with Disabilities (CRPD Committee) made these observations on Australia’s first periodic report on its compliance with the CRPD:

The Committee notes with concern that despite the adoption of emergency response and mitigation plans at the local and state levels, disability needs are often not explicitly factored into disaster response measures, and that there are as yet no specific measures in national plans to address emergency intervention strategies for persons with disabilities.

37. In October 2019, in its concluding observations on Australia’s combined second and third periodic reports, the CRPD Committee stated that it remained concerned about the lack of nationally consistent emergency management standards that ‘ensure access to disability-specific and disability-responsive support during emergencies’. The CRPD Committee recommended that Australia, in:

close consultation with representative organisations of persons with disabilities, establish a fully accessible and inclusive mechanism to engage with persons with disabilities in the implementation and monitoring of the [Sendai Framework for Disaster Risk Reduction 2015–2030].

44 The CRPD Committee is the body of independent experts which monitors the implementation of the Convention by the States Parties.
45 Exhibit 5.19.10, EXP.0003.0002.0145 at 0146.
46 Exhibit 5.19.11, EXP.0003.0001.0001. The Sendai Framework is an international disaster risk management agreement which was endorsed by the UN General Assembly following the 2015 UN World Conference on Disaster Risk Reduction.
Article 31: data

38. Article 31 of the CRPD relates to the collection, disaggregation and dissemination of statistics and data relevant to the implementation of the obligations of States Parties. Article 31 states that:

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.

…

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Articles 25 and 26: health and independence

39. Article 25 obliges States Parties to:

recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

40. Article 26(1) requires States Parties to make available to persons with disabilities comprehensive habilitation and rehabilitation services, and to take effective and appropriate measures:47

   to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

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Australian Government acknowledgements

41. The Australian Government’s submissions quite properly acknowledge a number of important matters. The Australian Government accepts that the COVID-19 pandemic has had a significant impact on people with disability and on those involved in the disability sector, in addition to its impact on the wider community and the general health system. The Australian Government also acknowledges that the preparations for and responses to the COVID-19 pandemic confronted significant challenges and lessons should be learned from the experience. The Australian Government states that it will continue to refine its approach as the pandemic evolves, including during the period of recovery.

42. The Australian Government’s submissions quote and apparently endorse the following observation in the Australian Health Sector Emergency Response Plan for Novel Coronavirus (Covid-19) (COVID-19 Plan), published in February 2020:

The Australian Government is responsible for ensuring the resources and systems required to mount an effective national response are readily available [including] ensuring that Australia meets its international obligations. [Emphasis added]

The Australian Government accepts that it should undertake a review of all existing emergency plans ‘for the purposes of identifying and modifying to include people with disability consistently with the rights set out in the CRPD’.

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48 Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014, at [7].
51 Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [137].
Counsel Assisting’s submissions propose that the next National Disability Strategy should specifically establish:

pathways to ensure persons with disability, through their representative organisations, are consulted and included at every level in the planning and response to other public emergencies.\(^{52}\)

The Australian Government’s submissions adopt this proposal but suggest that it should be amended to eliminate the reference to representative organisations. This would allow the consultation process to incorporate a wider range of views and not be restricted to representative organisations alone.\(^{53}\) The Australian Government therefore accepts the proposition that people with disability as well as their representative organisations should be included at every level in planning for and responding to emergencies.

The Australian Government’s submissions stated that the Department of Health ‘acknowledges’ Counsel Assisting’s proposed recommendation that:

the Commonwealth Government fund and support people with disability and their organisations to participate in consultation with it during the COVID-19 pandemic.\(^{54}\)

We take that to mean that the Department of Health agrees that funding and support of this kind is necessary if people with disability and their representative organisations are to participate effectively in the planning responses to the pandemic.

The Australian Government’s acknowledgements of its international obligations are both appropriate and significant. Australia has a federal system of government under which the states retain

\(^{52}\) Submission of Counsel Assisting, Public hearing 5, 4 September 2020, DRC.9999.0019.0001 at [432(b)].


\(^{54}\) Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [123]. The Submissions go on to say that the Department of Health will consider support for individuals but ‘does not routinely fund disability representative organisations’.
responsibilities for delivering essential services such as health and education. But the federal structure does not mean that the Australian Government can disclaim responsibility for ensuring compliance with its international obligations. More specifically, the Australian Government cannot disclaim responsibility for ensuring compliance with Australia’s obligations under the CRPD on the ground that the states provide certain essential services such as testing for COVID-19 or providing all state school children with online education during government imposed ‘lockdowns’. The Australian Government has both the legislative power under domestic law and the responsibility under international law to ensure that the human rights of people with disability outlined in the CRPD are respected and enforced within Australia.  

Forgotten and ignored

ABB*

ABB is the mother of two children and gave evidence at the hearing. ABB’s daughter is 12 years old. She has Down syndrome, limited speech and a sensory processing disorder. She likes going to school and is ‘usually quite excited to put her uniform on in the morning’.

ABB decided early on that she wanted her daughter ‘to have a fully inclusive life in the family, the community and especially at school’. ABB’s daughter had just started high school in a mainstream setting when schools closed due to the pandemic.

55 The territories are in a different constitutional position as the Commonwealth Parliament has power to make laws affecting the territories: Commonwealth of Australia Constitution Act (Cth) s 122. In practice the position of the territories is similar as to that of the states.

56 See, Commonwealth of Australia Constitution Act (Cth) s 51 (xxix); Commonwealth v Tasmania [1983] HCA 21; (1983) 158 CLR 1 (Tasmanian dams case). See also, Matthew Stubbs, Adam Webster and John Williams, Persons with Disability and the Australian Constitution, report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, October 2020, pp 27-29.
ABB gave evidence that ‘most conversations [at her daughter’s school] were around the lack of funding rather than the supports they could provide’. ABB felt that school’s lack of preparation was ‘evident in the work which was coming home’. ABB questioned the work her daughter was set at the beginning of the year, which were ‘mostly colouring activities, very low level tasks’. The school told her ‘to be patient and wait for the school to settle all the students’.

ABB said these experiences were exacerbated by the COVID-19 pandemic. She said the school closure ‘was quite a difficult time for us, especially in the early stages where I felt that my daughter was an afterthought’. ABB said her daughter’s lack of contact with her teachers and classmates resulted in her becoming very inactive, withdrawn and unmotivated.

ABB had to ‘explicitly ask’ for her daughter to be added to the Google Classroom, which happened a few days after students began learning remotely. ABB took it upon herself to modify the work which was provided to the remainder of the class in order to show teachers what kind of activities her daughter was capable of. ABB said that once her daughter was included in the Google Classroom, this gave her insight into the curriculum and ‘really reaffirmed that there’s a real disconnect between my daughter’s learning and what happens in the classroom’.

Reflecting on her daughter’s education, ABB said:

…I think one of the biggest issues was the obvious lack of preparation in terms of supporting my daughter’s learning, especially during the COVID shutdown. I think at the core of this there is some deeply rooted ableism where there is a view that students with disability are an add-on, a burden, that they belong somewhere else.

ABB said that when her daughter is included she observes her becoming ‘more confident and more independent’ and ABB sees ‘a sense of pride on her face’.

* The identity of ABB is the subject of non-publication directions made by the Royal Commission. She was identified through the use of the pseudonym in the hearing. This pseudonym is used throughout this report.
46. The evidence at Public hearing 5 echoed what people with disability were telling the Royal Commission from the very outset of the pandemic: many people with disability were very anxious, stressed and frightened as they found themselves severely affected by an unprecedented health crisis. Their already high levels of anxiety, stress and fear were immeasurably heightened by the feeling that they had been forgotten by governments and the general community and that the responses to the pandemic had ignored the severe challenges they faced.57

47. On 21 April 2020, the University of New South Wales Social Policy Research Centre published a report entitled *The disability workforce and COVID-19: initial experiences of the outbreak.*58 The report, which was prepared for the Health Services Union, Australian Services Union and United Workers Union, drew on data from a survey of 2,341 disability workers conducted in March 2020.59 The survey found that disability workers were concerned that:

- the lack of PPE being supplied to staff and clients was creating risks for clients
- their organisations’ safety protocols were inadequate to protect clients and service providers were slow to respond to the risks posed by COVID-19
- they had insufficient resources to support clients effectively during the pandemic.60

57 For example, see Submission of Counsel Assisting, Public hearing 5, 4 September 2020, DRC.9999.0019.0001 at [367-372]; Exhibit 5.26, Statement of Kirsten Deane, 12 August 2020, at [19-22]; Transcript, Kirsten Deane, Public hearing 5, 19 August 2020, P-137 [44-47]; Transcript, Kirsten Deane, Public hearing 5, 19 August 2020, P-138 [1-3].
58 Exhibit 5.58, DRC.2000.0003.0395.
59 Exhibit 5.58, DRC.2000.0003.0395 at 0398.
60 Exhibit 5.58, DRC.2000.0003.0395 at 0398.
48. On 19 August 2020, Every Australian Counts published a report entitled “Left out and locked down” The experiences of people with disability and their families during COVID-19. The report sets out the results of a survey conducted between the end of April and the beginning of June. Every Australian Counts received 721 responses to the survey, primarily from people with disability or their families, but also from a small number of people who work in the disability sector, including advocates. Ms Kirsten Deane, Campaign Director of Every Australian Counts, said in evidence that the survey showed that:

People felt that government had forgotten about them and they felt that government didn’t really have a good idea of the very real challenges that they were facing at this time. And they noticed it in small ways with things like the fact that the Prime Minister or Premiers didn’t really mention people with disability or their families in their press conferences, or mention them in the plans that they were releasing...

49. Ms Deane went on to say that:

probably the biggest thing was the fact that people who were on the Disability Support Pension, or who received the carer’s payment were not given the additional coronavirus supplement as other groups were. And that was particularly frustrating because it happened right at the same time that people were reporting to us that their costs had increased.

50. This feeling of being forgotten, left behind and left out was borne out by the evidence at Public hearing 5 about Australia’s pandemic plans both prior to COVID-19 and in the early days of the COVID-19 pandemic.
Fiona *

Fiona is in her early 60s and is deafblind, has dementia and mobility issues. She lives in an aged care facility.

Fiona’s aged care facility banned visitors in March 2020. This ban extended to support workers from the Deaf Society who regularly visited to communicate with Fiona using tactile sign language.

The ban on visitors meant that Fiona was isolated for 6 weeks within her aged care facility. Fiona was also banned from going outside. None of the staff members at the aged care facility were able to communicate with Fiona and explain the reason for the restrictions. She had no idea why her support workers had stopped visiting her and taking her for outings.

Staff from the Deaf Society tried to negotiate with the aged care facility so that someone would be permitted to meet Fiona and explain the pandemic and subsequent lockdown to her. Ms Jackson of the Deaf Society and Deaf Services said that the aged care facility ‘um’ed and ‘ah’ed about the request. Staff from the Deaf Society were eventually able to negotiate for someone to visit Fiona for 30 minutes.

When a support worker was eventually able to visit, he said that her ‘mental health had suffered a serious decline due to six weeks of no communication’. While staff from the Deaf Society were eventually able to visit Fiona on a daily basis, at the end of July, the aged care facility decided that its residents were no longer allowed to go on outings anymore. Ms Jackson said that Fiona has received this news ‘with great disappointment’ because she ‘really, really, enjoyed these outings’.

* Name has been changed and some details removed to protect people’s identities. This narrative is based on the evidence of Leonie Jackson, Executive Manager at the Deaf Society and Deaf Services Ltd.
The early response

A chronological account

51. Since 2011, the Australian Government and state and territory governments have had National Health Emergency Response Arrangements (National Arrangements) in place to oversee responses to significant national health emergencies. The National Arrangements are overseen by the Australian Health Protection Principal Committee (AHPPC). The AHPPC comprises all state and territory Chief Health Officers and is chaired by the Australian Government Chief Medical Officer (CMO).

52. Prior to the COVID-19 pandemic, the Australian Government Department of Health formulated emergency, pandemic and communicable disease plans. None of these plans specifically referred to the need to address the difficulties likely to be experienced by people with disability, or to the provisions of the CRPD. These included the Emergency Response Plan for Communicable Diseases Incidents of National Significance (September 2016), the Emergency Response Plan for Communicable Disease Incidents of National Significance (May 2018) and the Australian Health Plan for Pandemic Influenza (August 2019). Dr Nick Coatsworth, the Deputy Chief Medical Officer of Australia, explained that:

> Health sector preparedness and response plans are prepared with the broad goals of protecting the health of all Australians, to minimise morbidity, mortality and the burden on the health system. The three plans … set out the high-level arrangements that the health sector will follow in response to a communicable disease outbreak or pandemic. They do not deal directly with any specific group rather they are plans that focus on the interactions between the Australian Government agencies, cross government
arrangements, and to support an integrated and coordinated response.\textsuperscript{65}

53. The Australian Government’s submissions acknowledged that the response to the COVID-19 pandemic could have been improved had there been:

- routine habits of consultation and collaboration between the Department of Health and the departments and agencies responsible for disability policy and programs before the pandemic.\textsuperscript{66}

54. National data on the rates of communicable diseases is collected by the Communicable Disease Network Australia (\textbf{CDNA}) under the National Notifiable Diseases Surveillance System (\textbf{NNDSS}). The NNDSS relies on notifications made by state and territory health authorities under the provisions of the public health legislation in their jurisdiction. As discussed further below, the CDNA is responsible for determining what flags or methods of disaggregation of data are used in the surveillance of communicable diseases, including whether or not ‘disability’ would be used as a flag for data on COVID-19 cases under the NNDSS.

55. Australia’s first case of COVID-19 was detected in January 2020.\textsuperscript{67} On 30 January 2020, the World Health Organization (\textbf{WHO}) declared the outbreak a Public Health Emergency of International Concern. On 7 February 2020, the NDIS Commission issued a Provider Alert. The alert warned NDIS providers about a ‘novel coronavirus outbreak’ but did not advise that any specific action should be taken.\textsuperscript{68}

56. By February 2020, the Department of Health was working on its plans and response to the pandemic.\textsuperscript{69} On 18 February 2020, the

\textsuperscript{65} Exhibit 5.44, Statement of Nick Coatsworth, 7 August 2020, at 3[1].
\textsuperscript{66} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [99].
\textsuperscript{67} Transcript, Anne Kavanagh, Public hearing 5, 20 August 2020, P-202 [24-25].
\textsuperscript{68} Exhibit 5.177, CTD.7200.0001.3464.
\textsuperscript{69} Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P-315 [33-37].
Department of Health released the COVID-19 Plan, which was designed to guide the Australian health sector’s response to the pandemic. It stated that planning at all levels would:

consider what is needed to protect the most vulnerable members of our communities, and address the needs of special groups, such as the aged care sector and Aboriginal and Torres Strait Islander peoples.

57. The COVID-19 Plan was activated on 27 February 2020.

58. There was no reference in the COVID-19 Plan to people with disability. Dr Coatsworth said the COVID-19 Plan was designed to guide the initial response of the Australian health sector to the virus. He said the COVID-19 Plan was intended to be a ‘living document’, to be updated as more was learned about COVID-19 and key at-risk groups. Mr Simon Cotterell, First Assistant Secretary, Primary Care Division at the Department of Health, accepted the failure to refer to people with disability was an ‘omission’ and that ‘in an ideal world’, people with disability would have been included among identified ‘at-risk’ groups in the COVID-19 Plan.

59. It is true that the COVID-19 Plan referred to ‘the most vulnerable members of our communities’ and ‘vulnerable groups’. These references, however, were vague and were no substitute for express references to and acknowledgments of the specific needs of people with disability. There is no evidence that any decision-maker referred to the provisions of the CRPD when the COVID-19 Plan was prepared. It is not surprising, therefore, that the CRPD did not inform...
the early response of the Australian Government to the challenges presented by the pandemic.

60. It is striking that neither disability representative organisations nor individual people with disability were consulted during the critical early period when emergency plans responding to the pandemic were being prepared. It is also striking that the NDIS Commission was not consulted prior to the release of the COVID-19 Plan.76 Ms Samantha Taylor, Registrar of the NDIS Commission, agreed that in the critical period between early February and mid-March 2020, there was not much direct communication between the Department of Health and the NDIS Commission.79 It was not until 27 March 2020 that the NDIS Commission was included in a stakeholder meeting that specifically considered the health responses for people with disability during the pandemic.80

61. On 25 February 2020, the Department of Health activated the Emergency Response Plan for Communicable Disease Incidents of National Significance (National Communicable Diseases Plan)81 for coronavirus at the request of the CMO. The National Communicable Diseases Plan noted the importance of communication strategies being:

   tailored to meet needs ranging across our community, particularly those in vulnerable groups. Support for mental health needs of the community as a whole should also be considered. Channels of communication should be carefully selected to ensure messages are received broadly across the community.82 [Emphasis added]

Despite the reference to ‘vulnerable groups’ the National Communicable Diseases Plan did not expressly mention the needs of or challenges faced by people with disability.

76 Exhibit 5.48, Statement of Samantha Taylor, 12 August 2020, at [94].
79 Transcript, Samantha Taylor, Public hearing 5, 21 August 2020, P-392 [32-35].
80 Transcript, Samantha Taylor, Public hearing 5, 21 August 2020, P-394 [21-25].
81 Exhibit 5.73, DRC.2000.0002.0367.
82 Exhibit 5.73, DRC.2000.0002.0367 at 0391. Mr Cotterell used ‘vulnerable’ to mean at risk of contracting the virus.
62. On 6 March 2020, Ms Taylor, on behalf of the NDIS Commissioner, attended briefing sessions led by the CMO. She said that she raised the importance of giving attention to the specific needs of people with disability in the government and health sector responses to COVID-19.  

63. On 9 March 2020, the NDIS Commission issued a Provider Alert advising NDIS providers of the COVID-19 outbreak and advising that some people with disability are more likely to be vulnerable to severe adverse effects associated with COVID-19. The Provider Alert set out NDIS providers’ obligations to continue to provide safe, quality supports and services and to manage risks of infection of NDIS participants in the course of providing registered supports. This included reinforcing staff hygiene practices and undertaking contingency planning in the event that staff were affected by COVID-19 and unable to work. The Provider Alert also referred to NDIS providers’ obligations to notify the NDIS Commission of any changes that adversely affected providers’ abilities to provide supports. This included any change or event that significantly affected a provider’s ability to comply with its conditions of registration or seriously impaired the provider’s ability to effectively conduct operations and deliver ongoing supports to NDIS participants.  

64. On 11 March 2020, the WHO declared COVID-19 to be a pandemic. On the same day, the Australian Government announced its $2.4 billion health response to COVID-19. That announcement stated that additional funding would be provided for primary care, aged care, hospitals and research, including telehealth consultations for ‘people with chronic diseases’ and ‘people who are immunocompromised’. The funding also included ‘$30 million in infection control training and

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83 Exhibit 5.48, Statement of Samantha Taylor, 12 August 2020, at [15-16].
84 Exhibit 5.178, CTD.7200.0001.3444.
86 Exhibit 5.42, Statement of Simon Cotterell, 10 August 2020, at [9].
programs for health and aged care workers’. Mr Cotterell confirmed that the contents of this package were not communicated directly to disability stakeholders.

65. On 12 March 2020, the AHPPC issued a statement recommending new testing criteria for health care workers providing care to patients or residents. In publishing the criteria the AHPPC recognised that health care workers ‘with direct contact with patients are more likely to be exposed to COVID-19’ and that testing:

is a method of early detection of transmission of COVID-19 in the community and an extra protective mechanism for the vulnerable people they treat in clinical practice.

‘Healthcare worker’ was defined by the AHPPC as ‘anyone working in the health and aged care sectors that has direct contact with patients or residents’. This definition did not expressly include disability support workers.

66. On 13 March 2020, the CDNA published the first version of the CDNA national guidelines for the prevention, control and public health management of COVID-19 outbreaks in residential care facilities in Australia (Residential Care Facilities Guidelines). The Residential Care Facilities Guidelines were designed to ‘assist public health authorities, residential care services, healthcare workers and carers

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88 Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P-330 [9-10].


91 Exhibit 5.76, DRC.2000.0002.1670.
by providing best practice information for the prevention and management of COVID-19 outbreaks in [residential care facilities].

Dr Coatsworth gave evidence that the aged care sector was the ‘focus’ of the first version of the Residential Care Facilities Guidelines. However, the Residential Care Facilities Guidelines defined ‘residential care facilities’ to include:

- disability services or other congruent accommodation settings …
- where residents are provided with personal care or health care by facility staff …

Neither the disability sector nor the NDIS Commission (or the National Disability Insurance Agency (NDIA)) was consulted on the development of the Residential Care Facilities Guidelines. Indeed the NDIS Commission only learned of the guidelines when they were published. Ms Taylor gave evidence that the Residential Care Facilities Guidelines were distributed to disability service providers but sometimes required modification or adaptation to be applied successfully. We return to these guidelines later.

On 16 March 2020, the Centre of Research Excellence in Disability and Health (CRE-DH) published an open letter calling on Australian governments to develop a targeted response to COVID-19 for people with disability, their families and the disability service sector. The open letter was signed by a number of distinguished disability researchers including Professor Anne Kavanagh and Professor Julian Trollor. The CRE-DH letter said that:

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92 Exhibit 5.76, DRC.2000.0002.1670.
93 Exhibit 5.44, Statement of Nick Coatsworth, 7 August 2020, at [12].
94 Exhibit 5.76, DRC.2000.0002.1670.
95 Transcript, Samantha Taylor, Public Hearing 5, 21 August 2020, P-392 [22]; Transcript, Graeme Head AO, Public Hearing 5, 21 August 2020, P-392 [24].
96 Transcript, Samantha Taylor, Public Hearing 5, 21 August 2020, P-392 [22].
97 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [201-206].
98 Both Professor Kavanagh and Professor Trollor gave evidence at Public hearing 5. See, Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020; Exhibit 5.36, Statement of Professor Julian Trollor, 7 August 2020.
Australians with disability are a vulnerable population in the COVID-19 pandemic because they are at elevated risk of morbidity and death due to underlying health conditions. This is frightening because:

- The *health sector* is under-prepared to meet the urgent health care needs of people with disability.
- The *disability service sector* will not be able to meet the care needs of people with disability.
- Information on what to do is not easily accessible. For example, some people may not understand why there is disruption to their usual daily care routines.

The Government has a targeted response for the aged care sector, but not for the disability sector. Both sectors have many similarities including congregated settings, a precariously employed and inadequately trained care workforce, and families and carers who may face significant challenges meeting the care needs of people with disability in Australia.\(^9\)

70. Also on 16 March 2020, the Australian Government published an infection prevention and control training program titled *How to protect yourself and the people you are caring for from infection with COVID-19*. The program was published online for carers across all sectors, including for disability support workers.\(^1\) Mr Cotterell gave evidence that as of 5 August 2020, 78,000 people working in the disability sector had completed the program.\(^2\)

71. On 18 March 2020, the Council of Australian Governments (COAG) Disability Reform Council\(^3\) met to discuss the national response to

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\(^9\) Exhibit 5.30.2, EXP.0031.0001.0013 at 0014.

\(^1\) Exhibit 5.42, Statement of Simon Cotterell, 10 August 2020, at [9], [14].

\(^2\) Exhibit 5.42, Statement of Simon Cotterell, 10 August 2020, at [14].

the COVID-19 pandemic and its potential impact on people with disability and the NDIS. The Disability Reform Council published a communique which emphasised the:

> importance of continual engagement with the disability sector to monitor the response to COVID-19 and ensure the needs of people with disability, their carers and providers are being met.\(^{103}\)

72. The communique identified priorities within the Australian Government’s COVID-19 response for people with disability, including ensuring:

- appropriate consideration is given to people with disability and the disability services sector in the health response to the COVID-19 pandemic
- continuation of services to NDIS participants through the extension and flexibility of NDIS plans
- appropriate plans are in place to respond to any workforce shortages that may arise as a result of COVID-19.\(^{104}\)

73. On 21 March 2020, the Minister for the NDIS announced a range of new measures intended to support NDIS participants and providers during the COVID-19 pandemic. These included a proactive outreach program administered by the NDIA, which would contact ‘high-risk participants’. The measures also included financial assistance to NDIS providers to support staff retention, and a 10 per cent COVID-19 loading on the price of some supports.\(^{105}\)

74. On 24 March 2020, the CRE-DH published a further statement noting the apparent lack of an integrated disability and health support response.\(^{106}\) It noted that the Australian Government had mobilised support for the aged care and health sectors but had not paid the

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\(^{103}\) Exhibit 5.141, EXP.0003.0003.0057.

\(^{104}\) Exhibit 5.141, EXP.0003.0003.0057.

\(^{105}\) Exhibit 5.199, DRC.2000.0002.0828.

\(^{106}\) Exhibit 5.30.4, EXP.0031.0001.0043.
same attention to the disability sector. It also pointed out that the response ‘has largely focused on changes to the NDIS process’. As a result, the impact of COVID-19 on the 90 per cent of people with disability who were not NDIS participants had not been considered.

75. On or around 26 March 2020, Mr Cotterell became aware of the CRE-DH’s two statements of concern, together with Professor Julian Trollor’s statement on *Access to COVID-19 prevention, screening and treatment of people with intellectual or developmental disability*. And, as already mentioned, on 26 March 2020 the Royal Commission issued its Statement of Concern about the response to the COVID-19 pandemic for people with disability.

76. Also on 26 March 2020, the Australian Government announced the expansion of coronavirus testing to include testing all health workers and all aged and residential care workers with a fever or acute respiratory infection. In areas where there was no community transmission, testing was expanded to ‘high risk settings’ where there were two or more ‘plausibly-linked’ cases, such as aged and residential care and rural and remote Aboriginal and Torres Strait Islander communities. Although this announcement did not expressly mention the disability sector, it did mention ‘residential care’. As has already been noted, the Residential Care Facilities Guidelines had defined ‘residential care facilities’ to include disability care facilities.

77. On 27 and 31 March 2020, the Department of Health held informal discussions with a small groups of stakeholders and with the

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107 Exhibit 5.30.4, EXP.0031.0001.0043 at 0044.
108 See, Report [3-4].
110 Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P-324 [6-23]; Exhibit 5.36.1, EXP.0015.0004.0052.
Department of Social Services and the NDIS Commission.\textsuperscript{112} It appears that the discussions were for the purpose of establishing an Advisory Committee and commencing work on a plan specifically addressing the interests and health needs of people with disability.\textsuperscript{113} The evidence does not reveal the identity of the stakeholders.\textsuperscript{114}

78. In late March 2020, the Department of Health established a dedicated email address for NDIS providers and self-managing participants who could no longer access PPE through conventional means to access PPE from the National Medical Stockpile.\textsuperscript{115}

79. On 2 April 2020, more than 70 Disabled People’s Organisations issued an open letter to the National Cabinet\textsuperscript{116} calling on all governments to take urgent pandemic measures for people with disability. The open letter identified 10 urgent action items, including:

- the need to guarantee continuity of supports for all people with disability
- expanding criteria for testing to include people with disability and their support persons
- expanding eligibility for the Coronavirus Supplement of $550 per fortnight to recipients of the Disability Support Pension.\textsuperscript{117}

80. On 2 April 2020, the Department of Health established the Advisory Committee on Health Emergency Response to Coronavirus (COVID-
19) for People with Disability (Advisory Committee). The Advisory Committee was (and is) chaired by Mr Simon Cotterell. Committee members include people with lived experience of disability, disability advocates, disability organisations, representatives of the disability services sector, researchers, and representatives from various parts of government. The Advisory Committee was required to:

- provide expert advice to inform the development of a Management and Operational Plan on the health care needs of people with disability, their families and the disability service sector, including access to COVID-19 screening, prevention and healthcare
- oversee the implementation of the Management and Operational Plan.

**Australian Government submissions**

81. The Australian Government’s submissions understandably were framed as responses to Counsel Assisting’s proposed findings and recommendations. In substance, however, the Australian Government made the following submissions about its responses during the period from the onset of the pandemic to the establishment of the Advisory Committee:

- While acknowledging that its early response to the COVID-19 pandemic might have been improved had there been greater collaboration between agencies responsible for disability programs, the Australian Government’s response was adequate having regard to the extreme time pressures and

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118 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [22].
119 Exhibit 5.42, Statement of Simon Cotterell, 10 August 2020, at Appendix A.
120 A list of the members of the Advisory Group is found at Exhibit 5.42, Statement of Simon Cotterell, 10 August 2020, at Appendix A.
121 Exhibit 5.98, CTD.1000.0001.0010.
the need to develop an overall community strategy to confront the emergency.\footnote{122} 

- Regular consultations took place with the ‘disability sector’ to advise and inform planning in response to the COVID-19 pandemic, even before the establishment of the Advisory Committee on 2 April 2020.\footnote{123} 

- Overall the disability sector performed well in protecting the health and wellbeing of Australians with disability, with the most significant impact experienced by a comparatively small proportion of the total number of people with disability in Australia.\footnote{124} This is said to be demonstrated by the fact that only 154 NDIS participants were reported to have contracted COVID-19 by 17 September 2020. 

- Undoubtedly people with disability, along with the population at large, experienced anxiety and fear, but these experiences should not be attributed to the actions of the Australian Government.\footnote{125} 

- In any event, the states and territories have primary responsibility for establishing, maintaining and operating public health services, including testing for COVID-19.\footnote{126} 

\footnote{122} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [108]. 
\footnote{123} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [35]. 
\footnote{124} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [55], [57]. 
\footnote{125} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [115-116]. 
\footnote{126} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [104], [106], [175].
Assessing the Australian Government’s early response

82. We accept that the early response of the Australian Government to the unprecedented threats posed by the COVID-19 pandemic\textsuperscript{127} had to be formulated under extreme time pressures, with policy makers facing the prospect of a potentially catastrophic outcome. If the emergency plans in place prior to the onset of the pandemic had specifically addressed and provided for the needs of people with disability, the Australian Government’s early response to the COVID-19 pandemic may have been more attuned to the extraordinary challenges faced by people with disability. Unfortunately, the health emergency, pandemic and communicable disease plans prepared by the authorities before January 2020 did not refer, much less address, the particular needs and concern of people with disability.

83. In our view, the Australian Government was responsible for two significant failings during the period between the onset of the pandemic in late January 2020 (when the WHO declared the outbreak a Public Health Emergency of International Concern) and the establishment of the Advisory Committee on 2 April 2020.

84. The first is that contrary to the Australian Government’s submission, neither the Australian Government nor its agencies made any significant attempts, prior to 2 April 2020, to consult with people with disability or their representative organisations when planning how to respond to the emerging crisis. Any involvement of people with disability was minor and peripheral to the actions of the Australian Government.

85. Since there were not significant attempts to consult, it is not surprising that the Australian Government did not provide funds to disability representative organisations specifically for the purpose of enabling

\textsuperscript{127} Except for the Spanish Influenza pandemic a century ago.
them to contribute their expertise and understanding of the issues to the planning process.

86. It is perhaps not entirely coincidental that the Advisory Committee, which included people with disability, was established soon after the Royal Commission’s Statement of Concern was released and people with disability and advocates began to voice their concerns about the lack of consultation. Whatever the motivation for establishing the Advisory Committee, the Australian Government is very likely to have responded much more quickly and robustly to the needs of people with disability had it and its agencies consulted with people with disability and their representative organisations from the very outset of the pandemic.

87. The second failing is related to the first. Neither the Australian Government nor its agencies considered in any systematic or sustained fashion what measures were required to support and protect the safety, health and wellbeing of people with disability during the early stages of the pandemic. As we have noted, none of the plans in place prior to the onset of the pandemic specifically addressed the needs of people with disability (see at [52] above). Some steps were taken by the NDIA and the Minister for the NDIS in March 2020. However, these were directed to service providers who were given responsibility for implementing the measures. In any event, the evidence suggests that they did little in the short term to ameliorate the serious difficulties being experienced by NDIS participants.

88. As Professor Kavanagh pointed out in her evidence, to the extent that the Australian Government responded at all to people with disability in the early stages of the pandemic, the responses relied heavily on the NDIA and access to NDIS funded services and supports. Those responses were limited in that the NDIA is not responsible for people

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128 Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020.
with disability who are not NDIS participants. Non-NDIS participants include people who have high support needs but are not able to satisfy the stringent ‘disability requirements’ specified in the governing legislation and are thus ineligible to participate in the NDIS. They include people with disability above the age of 65 who are ineligible to participate in the NDIS. They also include people with disability who may be eligible to join the NDIS but who have not yet done so.

89. It is true, as the Australian Government contends, that not all the 2.4 million people under the age of 65 reported to have a disability were necessarily disproportionately affected, or likely to be disproportionately affected by the pandemic. But very large numbers of people with disability were affected. In 2018, there were around 728,800 people under the age of 65 years who experience what the Australian Bureau of Statistics calls ‘profound or severe’ disability (equivalent to around 30 per cent of people with disability under 65 years of age). However, in June 2020, there were only 392,000 NDIS participants. Given the stringent eligibility criteria that must be satisfied for a person to participate in the NDIS, it is very likely that

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129 National Disability Insurance Scheme Act 2013 (Cth) s 24(1). Among other requirements the person’s impairment must result in substantially reduced functional capacity and may be permanent (or likely to be permanent). Other people who have profound or severe disabilities may not be NDIS participants for reasons not examined during the hearing, including geographical location and the timing of their state joining the NDIS system, they may be awaiting the outcome of their application, they may be ineligible to apply for the NDIS because of their citizenship or visa status or other reasons.

130 National Disability Insurance Scheme Act 2013 (Cth) s 22.

131 This is due to the broad definition of ‘disability’ as it is used in data collection schemes such as the Survey of Disability, Ageing and Carers published by the Australian Bureau of Statistics. This definition includes people who have difficulties caring for themselves, moving around their environs and communicating; those who are restricted in their education and employment; and those who are not limited in core activities or restricted in education or employment but have other restrictions. See, Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [58-61].

132 The Australian Bureau of Statistics defines people with a profound or severe disability as those people needing help or assistance in one or more of the three core activity areas of self-care, mobility and communication, because of a disability, long-term health condition (lasting six months or more) or old age. See, Australia Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of findings methodology, 24 October 2019, Glossary: Core activity limitation.

very nearly all NDIS participants are people who have ‘profound or severe’ disability, as defined by the Australian Bureau of Statistics.\textsuperscript{134}

If this is correct it follows that around 330,000 people determined by the Australian Bureau of Statistics to be people with ‘profound or severe’ disability (about 45 per cent of such people) are not NDIS participants. They were not included in the Australian Government’s NDIS-focused COVID-19 response.

90. The evidence demonstrates the COVID-19 pandemic has had a very substantial impact in many different ways on the health, safety and wellbeing of a great many people with disability. In our view, it is no answer to the evidence to claim that the most severe health impacts on people with disability, such as people becoming seriously ill from the virus, have been experienced by a small proportion of the total number of people with disability in Australia. Nor is it an answer to contend that the strategies put in place have been largely effective in protecting the general population from the virus.

91. Counsel Assisting’s Submissions contend that it is open to find that the Australian Government has not developed:

- a disability inclusive approach to planning for emergencies that takes into account and incorporates the [provisions of the] CRPD.\textsuperscript{135}

Counsel Assisting’s Submissions also invite a finding that:

- the normative content of the CRPD has not informed the [Australian Government’s] response to COVID-19 for people with disability.\textsuperscript{136}

\textsuperscript{134} Both the NDIS eligibility criteria and the Australian Bureau of Statistics definition are focused on the effect of an impairment on a person’s functional capacity. See above, nn 116, 118. Note that in certain circumstances, a child with developmental delay may be entitled to early intervention supports under the \textit{National Disability Insurance Scheme Act 2013} (Cth): see s 25(1)(a)(iii), (b), (c), (3). In June 2020; 8,200 children received early intervention supports under the NDIS: National Disability Insurance Agency, \textit{NDIS Quarterly Report to disability ministers}, 30 June 2020, p 24.

\textsuperscript{135} Submission of Counsel Assisting, Public hearing 5, 4 September 2020, DRC.9999.0019.0001 at [452(a)].

\textsuperscript{136} Submission of Counsel Assisting, Public hearing 5, 4 September 2020, DRC.9999.0019.0001 at [452(b)].
92. These submissions reflect the view expressed by Ms Kayess that during the pandemic the Australian Government had not fully implemented its obligations under article 11 of the CRPD, particularly in view of the concluding observations made by the CRPD Committee in October 2019 (see at [37] above).\textsuperscript{137}

93. The Australian Government’s submissions argue that article 11 does not require Australia to take a series of specific steps to comply with its obligations under the article.\textsuperscript{138} While that may be correct, it is difficult to maintain that before and during the early stages of the pandemic, the Australian Government in accordance with its obligations under international law acted by taking:

\begin{quote}
all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including …
humanitarian emergencies and the occurrence of natural disasters\textsuperscript{139}
\end{quote}

94. Emeritus Professor Ron McCallum adopts a more expansive interpretation of Australia’s obligations under article 11 of the CRPD than the interpretation advanced by the Australian Government. In an important research report prepared for the Royal Commission, Professor McCallum concludes that:

\begin{quote}
Australia is working to ensure that its people are protected and cared for when disasters occur. \textbf{However persons with disabilities and their representative organisations have not been adequately considered or included in planning thus far in this area as required by the CRPD.}\textsuperscript{140} [Emphasis added]
\end{quote}

\textsuperscript{137} Exhibit 5.19, Statement of Rosemary Kayess, 13 August 2020, at [16], [47-48].
\textsuperscript{138} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [143].
95. For these reasons, we do not accept that the Australian Government can escape responsibility for its failings in the early stages of the pandemic by claiming that the states and territories have primary responsibility for delivering health and other services to the community, including to people with disability.\textsuperscript{141} The Australian Government has the fundamental responsibility to ensure that Australia meets its obligations under international law. It also has the powers and financial resources necessary to fulfil that responsibility. It is significant that the Australian Government allocated $115.5 billion for health in the 2020–2021 Budget, including more than $16 billion towards the emergency health response to the COVID-19 pandemic.\textsuperscript{142}

**Findings and recommendations**

96. We make the following findings concerning the responses of the Australian Government to the COVID-19 pandemic during the period from the outbreak of the pandemic in January 2020 until the establishment of the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability on 2 April 2020.

96.1 During the early stages of the COVID-19 pandemic no agency of the Australian Government, including the Department of Health and other agencies responsible for disability policy, made any significant effort to consult with people with disability or their representative organisations. Even allowing for the novel challenges presented by the coronavirus this was a serious failure.

\textsuperscript{141} Report, [45].
96.2 The failure to consult during the critical early period contributed to the Australian Government neglecting to develop policies specifically addressing the needs of people with disability and the challenges confronting them in an emergency unprecedented in modern times.

96.3 The failure of the Australian Government to consult people with disability and the related failure to develop a plan specifically addressing the needs of and challenges faced by people with disability produced serious adverse consequences for many people with disability. These consequences varied depending on local circumstances but they included:

- extreme stress and anxiety related to fear of contracting coronavirus because of exposure to different support staff and the absence of adequate PPE for support staff and people with disability themselves
- the sudden loss of essential support services in the absence of programs designed to ensure continuity of such services for people with disability, especially those living in closed environments
- impaired health and wellbeing due to an inability for prolonged periods to access essential supplies such as food and medications
- significant distress, particularly among people with cognitive disability, due to the lack of clear and consistent information about the pandemic and the measures taken to control it
- threats to mental health due to a belief by some people with disability, including those in disability accommodation settings, that they had been forgotten and ignored, which was exacerbated by enforced isolation from family, friends and social networks and the absence of strategies to ameliorate the consequences of isolation.
96.4 In the absence of comprehensive data about the rates of COVID-19 infection and death among people with disability we are unable to determine whether any of the infections or deaths could have been prevented with better planning for the disability sector. But the evidence does not allow us to reject the hypothesis that better planning may well have done so.

**Recommendation 2:**
The Australian Government should explicitly commit to ensuring that all agencies responsible for planning and implementing responses to the COVID-19 pandemic and any future emergencies establish and implement formal mechanisms for consulting with and involving people with disability and disability representative organisations in planning and giving effect to the responses.

**Recommendation 3:**
The Australian Government should provide the funding and support required for disability representative organisations and, where appropriate, individual people with disability to participate in consultations with Australian Government agencies and advisory bodies responsible for planning and implementing policies and programs to safeguard the health, safety and wellbeing of people with disability during the COVID-19 pandemic and any future national emergency.

**Recommendation 4:**
The Australian Government should identify any gaps in the current consultation processes employed by departments and agencies which have responsibility for the safety, health and wellbeing of people with disability during the COVID-19 pandemic or other national emergencies. This process should include but not be limited to the Australian Government Department of Health, the National Disability Insurance Agency and the NDIS Quality and Safeguards Commission.
The later responses

Rudy*

Rudy is 12-year-old boy with autism who lives with his parents in Victoria. He is ‘full of energy, with a cheeky glint in his eye’ and ‘enjoys a wonderful, unique sense of humour’. He also ‘faces a mountain of adversity each day’.

Rudy’s parents explained in a submission that ‘with his severe autism … generalised anxiety disorder and complex behaviours’, Rudy’s days are filled ‘with long drives and stopping at playgrounds’. These outings meet his basic needs to stay regulated at the appropriate level of stimulation – a ‘delicate balance and critical to his wellbeing’.

‘Should Rudy not stay sufficiently regulated without access to playgrounds, a real risk is another crisis admission into … [a] neuro-psychiatric ward … including a very traumatising ED [emergency department] experience … involving physical restrictive practices by a team of orderlies, Rudy being shackled to a bed and pumped with enough sedative to knock out multiple adults whilst his anxieties spike out of control.’

When the COVID-19 related Restricted Activities Direction took effect in April–May 2020 and the intention to close playgrounds was announced, Rudy’s parents said they promptly sought exemption for Rudy to use quiet country playgrounds. They made a second request when the easing of restrictions was announced. Both requests were denied on the grounds that the Direction did not provide for any exemptions.

‘What we got was a complete disregard for a severely disabled person’s wellbeing and support needs,’ said Rudy’s parents.

‘General community health measures were applied in a way that potentially makes the already extremely challenging life circumstances of a severely disabled child like Rudy much worse.’

* Name changed and some details removed to protect people’s identities. Narrative based on a submission to the Royal Commission. Note that the submission and this narrative did not form any part of the evidence at the public hearing discussed in this report.
97. As we have noted, the Advisory Committee was established on 2 April 2020.\textsuperscript{143} From mid-April 2020, it met every week. Since 19 May 2020 it has convened every fortnight,\textsuperscript{144} and it has met on a monthly basis since 30 June 2020.\textsuperscript{145} The ‘Key Outcomes’ of the Advisory Committee’s meetings held between 21 April 2020 and 28 July 2020 were in evidence.\textsuperscript{146}

98. On 16 April 2020, the National Cabinet approved the Management and Operational Plan for People with Disability (Management and Operational Plan) and it was published the following day.\textsuperscript{147} The overall Management and Operational Plan committed the Australian Government to undertake ‘a range of specific measures relevant to the health of people with disability’ in the context of COVID-19 including:

Coordinating the implementation of the Plan, in partnership with the Advisory Committee …

…

Coordinating and communicating with the states and territories … to support effective communication and health service provision for people with disability in response to COVID-19.

Preparation and dissemination of national guidelines, procedures and other resources to support [the] Management and Operational Plan.

Mobilising the resources of the National Medical Stockpile, and State/Territory resources where applicable, to support the

\textsuperscript{143} Report, [80].
\textsuperscript{144} Exhibit 5.5.6, CTD.1000.0001.0379.
\textsuperscript{145} Exhibit 5.5.8, DRC.2000.0002.0001 at .0002. Despite the Advisory Committee deciding it would meet monthly at its tenth meeting on 30 June 2020, an extraordinary meeting was held on 17 July 2020: Exhibit 5.106, DRC.2000.0002.1331.
\textsuperscript{146} These records relate to the fourth to twelfth meetings of the Advisory Committee. Exhibit 5.99, CTD.1000.0001.0372; Exhibit 5.100, CTD.1000.0001.0375; Exhibit 5.101, CTD.1000.0001.0377; Exhibit 5.102, CTD.1000.0001.0381; Exhibit 5.103, CTD.1000.0001.0379; Exhibit 5.104, CTD.1000.0001.0373; Exhibit 5.105, DRC.2000.0002.0001; Exhibit 5.106, DRC.2000.0002.1331; Exhibit 5.107, DRC.2000.0002.1332.
\textsuperscript{147} Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P-338 [44].
appropriate provision of ... PPE and other resources ... to people with disability, their families, carers and support workers in health and disability care settings.

Developing and supporting a national communications plan specific to people with disability ...\textsuperscript{148}

99. It appears from the records of the Advisory Committee that the ‘key outcomes’ included the following:

- advising state and territory government departments of justice, health and education about supports and communication strategies that are necessary for people with disability during the pandemic and recovery process\textsuperscript{149}

- reviewing the Management and Operational Plan,\textsuperscript{150} including incorporating into it a document prepared by the Australian Human Rights Commission entitled \textit{Protecting the rights of people with disability: Guidelines on human-rights based decision making in the context of COVID-19}\textsuperscript{151}

- providing advice to the Department of Health about the development of plain English and Easy Read versions of the Management and Operational Plan

- identifying the need to develop COVID-19 data for people with disability within data collected by the CDNA\textsuperscript{152}

\begin{itemize}
\item Exhibit 5.80, DRC.2000.0002.0551 at .0561.
\item Exhibit 5.5.4, CTD.1000.0001.0377; Exhibit 5.5.5, CTD.1000.0001.0381 at 0382; Exhibit 5.5.6, CTD.1000.0001.0379.
\item This appears to have occurred multiple times. See, Exhibit 5.5.3, CTD.1000.0001.0375; Exhibit 5.5.6, CTD.1000.0001.0379.
\item Exhibit 5.100, CTD.1000.0001.0375.
\item Exhibit 5.99, CTD.1000.0001.0372; Exhibit 5.100, CTD.1000.0001.0375; Exhibit 5.102, CTD.1000.0001.0381.
\end{itemize}
• emphasising that government responses to the COVID-19 pandemic should not focus solely on people with disability who utilise the NDIS\textsuperscript{153}

• recognising that psychosocial disability should be recognised in Australia’s National Pandemic Mental Health Plan.\textsuperscript{154}

100. Two major government announcements were made after the Advisory Committee first met. On 27 April 2020, the Minister for the NDIS announced several policy measures, including authorising eligible NDIS participants to use existing NDIS funding over a five-month period to purchase low-cost assistive technology, including smart devices, to facilitate access to disability supports.\textsuperscript{155}

101. On 28 April 2020, the Minister for Health announced that 500,000 additional masks had been set aside for the disability sector.\textsuperscript{156} This announcement was welcomed in the Key Outcomes of the Advisory Committee’s fifth meeting on 29 April 2020.\textsuperscript{157}

102. On 13 May 2020 the NDIS Commission released a document entitled *Coronavirus (COVID-19) Outbreak preparedness, prevention and management*. The document encouraged registered NDIS providers of ‘disability accommodation settings’ to review the Residential Care Facilities Guidelines. But the NDIS Commission did not draw attention to the differences between disability and aged care accommodation to assist service providers in applying the Residential Care Facilities Guidelines to specialist disability accommodation.\textsuperscript{158}

\textsuperscript{153} Exhibit 5.5.2, CTD.1000.0001.0372.
\textsuperscript{154} Exhibit 5.5.6, CTD.1000.0001.0379.
\textsuperscript{155} Exhibit 5.123, DRC.2000.0002.0704.
\textsuperscript{157} Exhibit 5.5.3, CTD.1000.0001.0375 at 0376.
\textsuperscript{158} Exhibit 5.48, Statement of Samantha Taylor, 12 August 2020, at [106-107].
The Advisory Committee

103. The establishment of the Advisory Committee was clearly a major step forward in developing a national response to the specific needs and circumstances of people with disability during the pandemic. Not everyone, however, was entirely satisfied with the Advisory Committee’s composition or with the contents of the Management and Operational Plan.

104. Ms Kayess acknowledged that people with disability were represented on the Advisory Committee but pointed out that they constituted only a minority of the membership. She considered it to be:

    unclear how this expertise was meaningfully prioritised and what weight their views and concerns were given.\(^{159}\)

105. The Key Outcomes of the Advisory Committee record that the meeting held on 2 June 2020 heard from people with disability about ‘their first hand experiences of life during the COVID-19 pandemic’.\(^{160}\) This appears so far as the records are concerned, to be the first time the Advisory Committee heard directly from people with disability about their own experiences. Since this was the ninth meeting of the Advisory Committee, Ms Kayess’s concerns may have some force.

106. Ms Kayess also expressed concern about the high level of the Management and Operational Plan and criticised the extent to which it relied on the NDIS and state and territory governments to implement it.\(^{161}\) In her view, the Management and Operational Plan was not accessible for people with disability and did not provide sufficient clarity for them.\(^{162}\) This assessment perhaps pays insufficient regard to the fact that plain English and Easy Read versions of the

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\(^{159}\) Exhibit 5.19, Statement of Rosemary Kayess, 13 August 2020, at [34]; Transcript, Rosemary Kayess, Public hearing 5, 18 August 2020, P-37 [21-24].

\(^{160}\) Exhibit 5.5.7, CTD.1000.0001.0373.

\(^{161}\) Transcript, Rosemary Kayess, Public hearing 5, 18 August 2020, P-37 [16-37]; Exhibit 5.19, Statement of Rosemary Kayess, 13 August 2020, at [30].

\(^{162}\) Transcript, Rosemary Kayess, Public hearing 5, 18 August 2020, P-37 [35-37].
Management and Operational Plan were published on the Department of Health website\(^\text{163}\) and disseminated by means of a communications strategy developed by the Advisory Committee in conjunction with the Department of Health.\(^\text{164}\) The evidence does not allow us to make a finding as to whether the Management and Operational Plan was disseminated in community languages. However, witnesses explained the importance of producing material that is culturally appropriate and in community languages to ensure critical emergency information is accessible to culturally and linguistically people with disability and their communities.\(^\text{165}\)

107. Professor Kavanagh, who is a member of the Advisory Committee, expressed a more favourable opinion about its creation and work. In her experience the government members of the Advisory Committee demonstrated a genuine willingness to listen to the views of representatives of the disability sector. Professor Kavanagh observed that:

> Government representatives on the Advisory Committee heard our suggestions and instead of saying ‘oh no, we can’t do that’ they would say ‘we’ll investigate and report back’. It was a model of how to develop policy in a collaborative way.\(^\text{166}\)

108. Professor Kavanagh said that she had noticed staff within the disability agencies of government working more closely with the health sector:

> For example, when hospitals in Victoria banned visitors, the Victorian Government listened when people with disability said that they needed a support worker with them. The Victorian Government responded by issuing a directive that people with disability who

\(^{163}\) Exhibit 5.5.4, CTD.1000.0001.0377.

\(^{164}\) Exhibit 5.5.3, CTD.1000.0001.0375 at 0376.


\(^{166}\) Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [148].

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need additional support can bring an additional person to the hospital, regardless of whether they were there for a COVID-19 related reason.  

109. Mr Cotterell acknowledged that the Advisory Committee has shown it would be useful for the Department of Health to have a routine body of that kind to be hearing from people with lived experience, experts, and relevant agencies and providers about the health needs of people with disability more generally. In its submissions, the Australian Government agreed to commit to the Advisory Committee continuing during the COVID-19 pandemic and the recovery.  

Findings and recommendations  

110. Although the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability or a similar body including representation of disability advocacy groups and individual people with disability should have been created before 2 April 2020, its establishment was a positive development. The Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability has played a useful role since its establishment in informing the responses of the Australian Government to protecting the safety, health and wellbeing of people with disability during the pandemic.

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167 Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [151].  
168 Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P-347 [3-8].  
169 Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [34].
Recommendation 5:

The Australian Government should ensure that the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability continues to function for the duration for the COVID-19 pandemic and the recovery period and that it receives sufficient funding and support to fully discharge its responsibilities.

Recommendation 6:

The Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability, or a similar body, including significant representation of disability advocacy groups and people with disability, should remain in place after the pandemic has come to an end and the recovery is complete. While such a body might meet only sporadically during ‘normal’ times, it should be capable of reactivation at very short notice in the event of a fresh emergency that might affect the safety, health and wellbeing of people with disability.

First Nations people with disability

111. In the first week of March 2020, the Australian Government established the Aboriginal and Torres Strait Islander Advisory Group on COVID-19 (First Nations Advisory Group) in response to the increased risk First Nations people face during a pandemic. The Advisory Group advises on health issues related to COVID-19 and reports to the AHPCC.

112. The First Nations Advisory Group consists of representatives from each state and territory, general practitioners, as well as Aboriginal and Torres Strait Islander epidemiologists. The role of the First Nations Advisory Group includes contributing to the development of,

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170 Transcript, Dr Jason Agostino, Public hearing 5, 20 August 2020, P-268 [26-27].
171 Exhibit 5.35, Statement of Dr Jason Agostino, 12 August 2020, at [34].
and advising on the implementation of, the *Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19): Management Plan for Aboriginal and Torres Strait Islander populations; Operational Plan for Aboriginal and Torres Strait Islander populations* (First Nations Operational Plan).\(^{172}\) The First Nations Operational Plan was published in March 2020.\(^{173}\)

113. The terms of reference for the First Nations Advisory Group do not expressly mention First Nations people with disability, nor does the First Nations Advisory Group include a representative from a First Nations disability organisation.\(^{174}\) Initially, the First Nations Operational Plan also did not expressly refer to First Nations people with disability.\(^{175}\) This omission was corrected in the July 2020 version of the First Nations Operational Plan.\(^{176}\)

114. Counsel Assisting’s submissions proposed that the Department of Health should consider amending the terms of reference of the First Nations Advisory Group to state expressly that it should provide advice with respect to First Nations people with disability. Counsel Assisting also proposed that the Department of Health consider extending membership of the First Nations Advisory Group to include First Nations people with disability. The Australian Government’s submissions accepted both proposals.\(^{177}\)

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\(^{172}\) Exhibit 5.35, Statement of Dr Jason Agostino, 12 August 2020, at [36].

\(^{173}\) The evidence does not reveal the precise date of publication.

\(^{174}\) Exhibit 5.35.3, EXP.0029.0003.0006.


\(^{176}\) Exhibit 5.34.4, DRC.2000.0002.0485 at 0495.

\(^{177}\) Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [89-90].
Recommendations

Recommendation 7:
The terms of reference of the Aboriginal and Torres Strait Islander Advisory Group on COVID-19 should be amended to state expressly that its work is to include providing advice with respect to First Nations people with disability.

Recommendation 8:
The membership of the Aboriginal and Torres Strait Islander Advisory Group on COVID-19 should be extended to include at least one member who represents the interests of First Nations people with disability.

Guidelines for outbreaks

115. We have pointed out that the first version of the Residential Care Facilities Guidelines published on 13 March 2020 were intended to apply to disability accommodation settings but were drafted without the involvement of the NDIS Commission or the disability sector.\(^\text{178}\) It remains the case that the NDIS Commission is not mentioned in the Residential Care Facilities Guidelines, despite three subsequent versions having been released and the guidelines stating that they apply to ‘residential physical or mental disability care’.\(^\text{179}\)

116. Ms Taylor acknowledged that the Residential Care Facilities Guidelines:

\[
\text{did not reflect the very particular nature of disability accommodation and the smaller scale and configuration of the types of accommodation services that have traditionally been in place in disability...} \text{180}
\]

\(^\text{178}\) Report, [66], [68].
\(^\text{179}\) Exhibit 5.77, DRC.2000.0002.1349.
\(^\text{180}\) Transcript, Samantha Taylor, Public hearing 5, 21 August 2020, P-395 [39-41].
Ms Taylor accepted, for example, that in most disability accommodation settings people do not have their own bathroom.\textsuperscript{181} Other common differences from residential aged care settings may include a lack of facilities for clinical waste, and the absence of diagnostic equipment. Disability accommodation settings are also unlikely to have a reception area or a formal process for the admission of residents.

117. Ms Taylor said that despite subsequently working on an amended set of guidelines intended to be for disability accommodation settings, the CDNA did not consider it necessary for these to be released.\textsuperscript{182} However, Ms Taylor said that she had been approached more recently to contribute to finalising guidelines that will apply to disability accommodation settings.\textsuperscript{183}

118. The NDIS Commission released its own document, entitled \textit{Coronavirus (COVID-19): Outbreak preparedness, prevention and management}, on 13 May 2020.\textsuperscript{184} In this document, which has since been updated, the NDIS Commission encouraged registered NDIS providers of disability accommodation settings to ‘review’ the Residential Care Facilities Guidelines. But the NDIS Commission did not issue specific advice identifying the differences between disability accommodation settings and residential aged care settings to assist providers to determine how the Residential Care Facilities Guidelines could be applied to disability accommodation settings.\textsuperscript{185}

119. In our view, it was unsatisfactory to leave providers of disability accommodation services in the position of having to ‘review’ and adapt the Residential Care Facilities Guidelines in the urgent circumstances of the COVID-19 pandemic (and potentially in the even more urgent circumstances of a suspected or confirmed COVID-19 pandemic).

\textsuperscript{181} Transcript, Samantha Taylor, Public hearing 5, 21 August 2020, P-396 [4-6].
\textsuperscript{182} Exhibit 5.48, Statement of Samantha Taylor, 12 August 2020, at [105].
\textsuperscript{183} Transcript, Samantha Taylor, Public hearing 5, 21 August 2020, P-396 [17-18].
\textsuperscript{184} Exhibit 5.48, Statement of Samantha Taylor, 12 August 2020, at [37].
\textsuperscript{185} Exhibit 5.48, Statement of Samantha Taylor, 12 August 2020, at [107].
local infection or outbreak). More was needed to provide adequate assistance to providers of disability accommodation services, particularly in circumstances where these accommodation settings often do not have the ‘facilities’ identified in the Residential Care Facilities Guidelines. The lack of more specific information had clear implications for the consistency of infection control and outbreak management within disability accommodation settings.

Findings and recommendations

120. We find that the Australian Government failed to give clear guidance to service providers about the differences between residential aged care settings and disability accommodation settings in relation to infection control and outbreak management.

Recommendation 9:

The Australian Government Department of Health in consultation with the NDIS Quality and Safeguards Commission and the National Disability Insurance Agency should prepare comprehensive guidelines specifically addressing the prevention, control and public health management of COVID-19 outbreaks in disability accommodation settings, taking into account the differences between residential aged care settings and disability accommodation settings.
Department of Health

121.  At the federal level, policy and program responsibility for disability sits within the social services portfolio. By contrast, responsibility for aged care sits within the health portfolio. While representatives from the Department of Health met from time to time with representatives from the Department of Social Services, the NDIA and the NDIS Commission, the evidence at Public hearing 5 points to a lack of integration between the health and disability responses to the pandemic.

122.  The establishment of the Advisory Committee and the matters addressed by the Advisory Committee between April and July 2020 have clearly illustrated that health and disability responses need to be considered together. This is a theme that has arisen not only in Public hearing 5, but also in other hearings of the Royal Commission.¹⁸⁶

123.  Mr Cotterell gave evidence that a section within the Department of Health is responsible for the development of policies concerning people with intellectual disability. He acknowledged no officer was specifically responsible for ensuring that the Australian Government complies with its obligation under article 31 of the CRPD to collect and monitor data relating to the health of people with disability. Mr Cotterell accepted that this was something the Department of Health needed to consider.¹⁸⁷

124.  Mr Cotterell agreed that the Department of Health should address all areas of disability, not only intellectual disability, as part of its efforts to improve.¹⁸⁸ He added that it would be a good idea for the Department of Health to have a mechanism in place to monitor the Australian Government’s compliance with the requirements of the CRPD in relation to the health of people with disability.¹⁸⁹

¹⁸⁶ For example, Public hearing 4: Health care and services for people with cognitive disability, Public hearing 6: Psychotropic medication, behaviour support and behaviours of concern.
¹⁸⁷ Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P 343 [19-35].
¹⁸⁸ Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P 347 [21-27].
¹⁸⁹ Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P 348.
Findings and recommendations

125. The evidence strongly supports the view that a single unit should be responsible for planning to protect and improve the health, safety and wellbeing of people with disability in emergencies such as the COVID-19 pandemic and more generally. This applies to planning for health emergencies, pandemics and communicable diseases. We are not able to conclude with certainty that the presence of a single unit of this kind within the Australian Government Department of Health at the outset of the COVID-19 pandemic would have produced better outcomes for people with disability. However, we find that it is very likely that had such a unit been in place the Australian Government Department of Health would have consulted with disability representative organisations and individual people with disability earlier than in fact occurred. Had these consultations taken place they may well have produced more effective plans for the protection of the health, safety and wellbeing of people with disability, particularly in the early stages of the pandemic. This was an opportunity lost.

Recommendation 10:

The Australian Government Department of Health should ensure that an appropriately resourced unit or team has specific responsibility for developing plans and programs to protect the health and wellbeing of people with disability, including during emergencies such as the COVID-19 pandemic. This unit should be responsible for coordinating health and disability responses to emergencies such as the COVID-19 pandemic. The unit should operate in addition to the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability and should work closely with that Committee.
Testing and screening for people with disability

126. Witnesses at Public hearing 5 gave evidence about their experiences in relation to COVID-19 testing. Concerns were raised around the availability, accessibility and appropriateness of information for people with disability.

127. The evidence, which is summarised in Counsel Assisting’s submissions, provided examples of the difficulties experienced by people with disability. These include:

- A person with disability waited nine days to be tested for COVID-19 at home. During this period the person had no disability support workers to provide assistance with meals or personal care. She ate muesli bars for sustenance and stayed in bed for the nine days.

- A person with intellectual disability called the Coronavirus Information Helpline 1800 in South Australia three times before he obtained information about how to be tested. This resulted in him being unable to attend work and significantly increased the stress he experienced pending the test.

128. The Management and Operational Plan released on 17 April 2020 acknowledged that testing for COVID-19 for people with disability required the usual practices to be modified. The Management and Operational Plan proposed that:

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190 Submission of Counsel Assisting, Public hearing 5, 4 September 2020, DRC.9999.0019.0001 at [485-504].
191 Exhibit 5.3, Statement of Ricky Buchanan, 4 August 2020, at [77-78].
192 Transcript, Rachel Spencer, Public hearing 5, 19 August 2020, P-121 [20]-P-131 [45]; Exhibit 5.25.2, IND.0033.0001.0017.
193 Exhibit 5.80, DRC.2000.0002.0551.
safe and effective, but less invasive, COVID-19 testing procedures should be available to people with disability, for example through telehealth services and GP home visits\textsuperscript{194}.

as safe and effective COVID-19 pathology testing becomes available, people with disability, their families, carers and support workers should be given priority for testing\textsuperscript{195}.

people with disability and those supporting them should have better access to diagnostic testing by being provided with information in a form that is appropriate to their needs such as Easy Read, braille and Auslan\textsuperscript{196}.

support workers should be informed how to support a person with disability who requires testing, and how to respond should the result be positive.\textsuperscript{197}

129. Dr Coatsworth was asked what COVID-19 testing arrangements were in place for people with disability after release of the Management and Operational Plan. He replied that the arrangements were ‘consistent with what was in place prior’.\textsuperscript{198} Dr Coatsworth accepted that not all COVID-19 testing facilities or arrangements are accessible to all people with disability. Nonetheless he insisted that access to testing can be provided through primary health care:

We have always taken the position that if there are any challenges with the … health sector response … the first port of call is through a primary health provider.\textsuperscript{199}

\textsuperscript{194} Exhibit 5.80, DRC.2000.0002.0551 at 0568.
\textsuperscript{195} Exhibit 5.80, DRC.2000.0002.0551 at 0573.
\textsuperscript{196} Exhibit 5.80, DRC.2000.0002.0551 at 0573.
\textsuperscript{197} Exhibit 5.80, DRC.2000.0002.0551 at 0573-0574.
\textsuperscript{198} Exhibit 5.44, Statement of Dr Nick Coatsworth, 7 August 2020, at [26].
\textsuperscript{199} Transcript, Dr Nick Coatsworth, Public hearing 5, 21 August 2020, P-363 [4-17].
Dr Coatsworth explained that:

prioritisation of testing was really anyone who had symptoms had a test. So there wasn’t a specific distinction made.200

130. Article 25 of the CRPD obliges the Australian Government to take all appropriate steps to ensure access to health services for people with disability. As the Australian Government’s submissions point out, in practice the states and territories conduct COVID-19 testing regimes. But the Australian Government has both the capacity and the duty under international law to act in cooperation with the states and territories to ensure that all people with disability have access to testing for COVID-19.

131. The Australian Government’s submissions accept that prior to mid-March 2020, no specific consideration was given to making testing or screening more accessible for people with disability who were unable to take advantage of arrangements for the general population.201 The Australian Government’s submissions identify a number of measures taken from mid-March 2020 to provide ‘supplementary support for testing’.202 The measures included providing testing in GP respiratory clinics, incorporating telehealth items in the Medicare Benefits Schedule and providing rapid COVID-19 point of care testing for First Nations people. While these measures were undoubtedly significant for the population at large and for First Nations people, they were not introduced specifically for the purpose of addressing the obstacles confronting people with disability wishing or being advised to be tested for COVID-19. This presumably explains why the Management and Operational Plan expressly addressed improving the testing arrangements available to people with disability.

200 Transcript, Dr Nick Coatsworth, Public hearing 5, 21 August 2020, P-366 [9-10].
Findings and recommendations

132. We make the following findings:

132.1 There appears to be no documentation demonstrating that any agency or department of the Australian Government responsible for disability policy and administration gave specific consideration prior to the release of the Management and Operational Plan for People with Disability on 17 April 2020 to putting in place arrangements to ensure as far as possible that all people with disability would have access to testing or screening for COVID-19.

132.2 We infer from the evidence that that failure to introduce measures to make COVID-19 testing accessible to all people with disability caused significant distress to people who were unable to access testing for COVID-19 during the early stages of the pandemic.

132.3 The Management and Operational Plan for People with Disability was a welcome development because it identified changes necessary to ensure that all people with disability have access to testing for COVID-19. However, the proposed changes had not been fully implemented by the date of the hearing.

Recommendation 11:

The Australian Government should implement fully the testing and screening arrangements identified in the Management and Operational Plan for People with Disability without delay.
Independent advocacy

Trevor*

Trevor is a young person with a cognitive disability.

When the pandemic commenced, Trevor was evicted from his shared housing arrangement because he did not understand and had trouble complying with physical distancing requirements.

Trevor was deemed to be ‘too high risk’ for public housing or alternative accommodation, such as living by himself in a motel. Trevor became homeless.

Trevor made a complaint with the help of the Ability Rights Centre and a disability advocate. However, according to the Ability Rights Centre at the time of its response to the Issues Paper, it was not clear whether Trevor’s new housing would be permanent.

* Name has been changed and some details removed to protect people’s identities.

This narrative is based on a response received by the Royal Commission to the Emergency Planning and Responses Issues Paper from the Intellectual Disability Services’ Ability Rights Centre. Note that the response and this narrative did not form any part of the evidence at the public hearing discussed in this report.
133. A consistent theme at the Royal Commission’s hearings has been the important role played by disability representative organisations in promoting the human rights of people with disability and in protecting them from violence, abuse, neglect and exploitation. Witnesses from disability representative organisations who gave evidence at Public hearing 5 stressed that independent advocacy organisations are indispensable in safeguarding the rights and interests of people with disability, especially during emergencies such as the COVID-19 pandemic.

134. Advocacy by disability representative organisations is crucial at two levels. The first is to represent and advocate for the interests of people with disability in policy making processes, also known as systemic advocacy. As representatives of the Australian Federation of Disability Organisations (AFDO) stated in the context of the pandemic, systemic advocacy is necessary to ensure that people with disability are ‘kept front and centre of any decisions concerning COVID-19’.203

135. Secondly, disability representative organisations (and individual advocates) advocate on behalf of individual people with disability. Ms Fiona Downing, the Senior Disability Advocate of Disability Justice Australia Inc, explained that the COVID-19 pandemic disproportionately affects people with disability because their health is at acute risk from COVID-19 and they are likely to experience greater risks to safety, health and wellbeing than others from the restrictions imposed on movement and contact. She argued that adequate funding for advocacy organisations is essential to ensure that people with disability can obtain the assistance they require when exposed to risks to their safety, health or wellbeing, for example where a support worker cancels a shift without warning or fails to wear PPE when

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203 Exhibit 5.20, Joint Statement of Ross Joyce and Patrick McGee, 11 August 2020, at [83].
providing support to a resident of specialist disability accommodation.²⁰⁴

136. The evidence clearly demonstrated that the COVID-19 pandemic had a significant impact on disability representative organisations. They had to put aside their regular activities ‘because the immediate crisis for people with disability [was] so great’.²⁰⁵ AFDO and its member organisations had to keep up with greatly increased workloads as they responded to a constantly changing policy environment and a rapid growth in urgent calls for advocacy specific to the situation created by COVID-19.²⁰⁶ For example, Mr Damian Griffis of the First Peoples Disability Network Australia (FPDN) said that the small staff of the FPDN had been ‘overwhelmed’ by the increased demand for services during the pandemic.²⁰⁷

137. It is clear that AFDO and its member organisations have experienced severe financial pressure during the pandemic. Ms Downing noted that funding for Disability Justice Australia Inc had not increased in real terms over the past decade, forcing it to close its advocacy waitlist for months at a time. She said that:

The failure to increase advocacy funding during a pandemic which disproportionately affects people with disability, means advocacy services are ill-equipped to assist people with disability whose health is at acute risk from the pandemic and who are subject to draconian restrictions on their freedom.²⁰⁸

138. The same views were expressed by other advocates.²⁰⁹

²⁰⁵ Transcript, Eleanor Gibbs, Public hearing 5, 18 August 2020, P-71 [7-9].
²⁰⁶ Transcript, Fiona Downing, Public Hearing 5, 18 August 2020, P-69 [36-38].
²⁰⁹ Exhibit 5.21, Statement of Fiona Downing, 12 August 2020, at [8]; Exhibit 5.28, Statement of Mary Sayers, 12 August 2020, at [123]; Transcript, Kirsten Deane, Public hearing 5, 19 August 2020, P-141 [28-29].
139. We have already recorded the Australian Government’s acknowledgment of Counsel Assisting’s proposed recommendation that the Australian Government should fund and support people with disability and their representative organisations to participate in consultations with it during the pandemic.\textsuperscript{210} The Australian Government’s submissions also noted that the Department of Social Services provides funding to disability representative organisations to provide systemic advocacy and representation for Australians with disability. The Australian Government states that the participation of disability representative organisations in consultations with government during the COVID-19 pandemic falls within the range of activities (already) covered by their grant agreements.\textsuperscript{211}

140. It appears, however, that the Australian Government provided a grant of $150,000 to the Disability Advocacy Network Australia (DANA) in response to representations from disability representative organisations about the need for advocacy outreach during the COVID-19 pandemic.\textsuperscript{212} It is not clear when this funding was provided, but the Australian Government’s submissions state that DANA has been reporting to it since early May 2020.\textsuperscript{213}

141. On 17 June 2020, DANA published findings from a survey on COVID-19 advocacy demand, indicating that overall demand had increased for 53 per cent of the respondents.\textsuperscript{214} The survey found that 42 per cent of advocacy organisations stated that they were unable to meet the increase in demand for advocacy services.\textsuperscript{215} This is consistent with the evidence at the hearing about increased demand, and unmet need during the pandemic.

\textsuperscript{210} Report, [44].
\textsuperscript{211} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [124].
\textsuperscript{212} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [131].
\textsuperscript{213} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [132].
\textsuperscript{214} Exhibit 5.279, DRC.2000.0003.0181 at 0185.
\textsuperscript{215} Exhibit 5.279, DRC.2000.0003.0181 at 0192.
142. We accept the Australian Government’s submission that systemic and individual advocacy fall within the range of activities covered by existing grant agreements between the Department of Social Services and disability representative organisations. That submission, however, overlooks the additional demands on the limited resources of disability representative organisations during an emergency such as the COVID-19 pandemic. Whatever may be said about the adequacy of the regular funding provided to disability representative organisations, the evidence shows that regular funding is not sufficient in extraordinary times. Indeed what appears to be a ‘one off’ grant to DANA seems to recognise that the usual levels of funding for disability representative organisations require supplementation during the pandemic.

143. The Advisory Committee, assuming it includes people with disability and is adequately resourced, is an important source of advice to the Australian Government on the measures that need to be taken by governments or official agencies to protect the safety, health and wellbeing of people with disability during the COVID-19 pandemic or future emergencies. But that is not enough of itself to ensure that people with disability are not subjected to avoidable harm during an emergency.

Findings and recommendations

144. We make the following findings:

144.1 The regular funding provided to disability representative organisations by the Australian Government was insufficient to enable them to cope with the substantially increased demand for systemic and individual advocacy from the outset of the COVID-19 pandemic. Had additional funding to disability representative organisations been provided, they would have been helped to meet the needs of many more people with disability and would have been assisted to make more
substantial and earlier contributions to the planning of responses.

144.2 It is virtually inevitable that substantially increased demand for the individual advocacy services of disability representative organisations will be a feature of any resurgence of the pandemic or any future emergency affecting the entire Australian community or significant sections of it.

**Recommendation 12:**

The Australian Government should immediately commit to providing supplementary funding to disability representative organisations for individual advocacy should there be a significant resurgence of COVID-19 in Australia.

**Recommendation 13:**

The Australian Government should commit to providing supplementary funding to disability representative organisations for individual and systemic advocacy whenever a new pandemic or major emergency (such as a natural disaster) occurs. The commitment should include establishing an emergency fund that can be drawn upon as soon as the need arises.

145. The evidence does not permit us to provide precise figures for the amount of supplementary funding required in the circumstances identified in Recommendations 12 and 13. However, the amounts should be commensurate with a careful assessment of the extent of the additional resources required to protect the safety, health and wellbeing of people with disability during the emergency.
Lack of data

Importance of data

146. It will be recalled that article 31 of the CRPD requires States Parties such as Australia to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the CRPD.²¹⁶

147. The COVID-19 Plan²¹⁷ published by the Department of Health on 18 February 2020 included ‘clear strategic approaches to the collection of national surveillance data’.²¹⁸ The COVID-19 Plan elaborated on this proposition as follows:

> The Australian Government is responsible for developing and maintaining systems to monitor communicable disease activity domestically and internationally and for communicating relevant information. Once a novel coronavirus with pandemic potential has arrived in Australia, these systems will be used for monitoring and analysis. Working together with state and territory representatives, the Australian Government will assess the risk of any potential outbreak threats to inform decision making about appropriate actions.

> State and territory governments are responsible for collecting surveillance data to contribute to the national picture and to inform the jurisdictional public health response.


²¹⁷ Exhibit 5.75, EXP.0003.0001.0001.

Other health sector stakeholders will also play a key role in surveillance activities and contributing to the national characterisation and understanding of the novel coronavirus of concern.\textsuperscript{219}

148. The importance of surveillance data for people with disability was also clearly identified by the Advisory Committee in April 2020.\textsuperscript{220}

149. And yet as at 17 August 2020 there was no publicly available national data that revealed the rates of COVID-19 infection or death for people with disability or of any sub-group of people with disability. Nor was any data publicly available that enabled the Australian community to assess the impact of COVID-19 on people with disability. Both Mr Cotterell, the most senior officer directly involved in coordinating the health response to assist people with disability,\textsuperscript{221} and Dr Coatsworth, the Deputy CMO, were asked by Ms Eastman SC how many people with disability had contracted COVID-19 since 22 January 2020 and how many people with disability had died due to COVID-19 since 22 January 2020. Neither was able to provide an answer.\textsuperscript{222}

**Groups of people with disability at increased risk**

150. On the second day of the hearing, 19 August 2020, the Minister for the NDIS issued a media release revealing numbers of cumulative cases of COVID-19 notified to the NDIS Commission since March 2020 and current active COVID-19 cases nationally, and by state and territory.\textsuperscript{223} The NDIS Commission had been notified of 86 COVID-19 cases among NDIS participants nationally since March 2020, 41 of which were ‘currently active’. The release also reported there were

\textsuperscript{219} Exhibit 5.75, EXP.0003.0001.0001 at 0020.  
\textsuperscript{220} Exhibit 5.99, CTD.1000.0001.0372; Exhibit 5.100, CTD.1000.0001.0375.  
\textsuperscript{221} Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P-313 [28-29].  
\textsuperscript{222} Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P-313 [42-45], P-314 [1-5]; Transcript, Dr Nick Coatsworth, Public hearing 5, 21 August 2020, P-350 [21-30].  

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145 COVID-19 cases among NDIS workers since March 2020, 88 of which were ‘currently active’.

151. The media release was a welcome development, but its utility was limited for the following reasons:

- As we have noted, NDIS participants comprise only a subset of people classified by the Australian Bureau of Statistics as having ‘profound or severe’ disability.\(^2\)
- The cumulative total of cases does not distinguish between deaths and recovered cases. This information is included in the Department of Health’s standard public reporting.
- The information is not published alongside other national statistics on the Department of Health website.
- The information was published on a weekly basis from 19 August to 1 October 2020 but no further updates have been published since then.\(^5\)

152. The available data does not permit firm conclusions to be drawn about the additional risks of contracting COVID-19 faced by people with disability living in disability accommodation settings. The very limited evidence does suggest, however, that people with disability living in disability accommodation settings are at greater risk of contracting COVID-19 and experiencing more serious health consequences than other people with disability.

153. The Minister’s media release stated that on 19 August there were 39 active COVID-19 cases among NDIS participants in Victoria.\(^6\) A media release issued on the same day by the Department of Health

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\(^2\) See, Report, [80-81].
and Human Services in Victoria noted that there were 19 active COVID-19 cases among NDIS participants in ‘NDIS homes’ (and 41 active cases among staff of the accommodation). It therefore appears that almost half (49 per cent) of COVID-19 cases in Victoria on 19 August were among NDIS participants living in disability accommodation settings. Since only five per cent of NDIS participants live in specialist disability accommodation, the data, limited though it is, suggests that people with disability living in specialist disability accommodation may have been over-represented among people with disability who contracted the virus.

154. This assessment is supported by the Management and Operational Plan released on 17 April 2020, which identified people with disability living in group residential settings as being at heightened risk of contracting COVID-19. The recently published Aged care and COVID-19: a special report by the Royal Commission into Aged Care Quality and Safety also lends support to the assessment. The report found that almost three quarters of all deaths from COVID-19 occurred among people in residential aged care facilities.

155. The fact remains, however, that there is no way at the national level to identify cases of COVID-19 that have been contracted by people living in specialist disability accommodation. Mr Cotterell, in his capacity as Chair of the Advisory Committee, held discussions with the CDNA about introducing ‘disability flags’ in that dataset, meaning that cases of COVID-19 could be linked to people with

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228 National Disability Insurance Agency, NDIS Quarterly report to disability ministers, June 2020, p 528.
229 Exhibit 5-90, EXP.0003.0003.0128 at 0136.
230 Exhibit 5-80, DRC.2000.0002.0551 at 0558.
232 It is unclear what the date of these discussion(s) was. However, on the basis of the ‘Next Steps’ listed in the Key Outcomes of the Advisory Committee’s fourth meeting, it was after 21 April 2020. See, Exhibit 5-5.02, CTD.1000.0001.0372.
disability contracting the virus. 233 The Department of Health submitted an agenda paper in support of this proposal to the CDNA’s meeting on 11 May 2020. 234 This proposal was rejected by the CDNA on 15 May 2020. 235

156. The Department of Health then made a request to the CDNA that ‘disability accommodation setting’ be included in the NNDSS exposure field on 29 May 2020, but this was not supported by the CDNA. 236 Instead, the CDNA used a broader ‘other residential care facility setting’ field. 237 In other words, it remains the position that the NNDSS does not collect information that enables the identification of cases of COVID-19 in specialist residential disability accommodation. As at 4 November 2020, the Department of Health has not publicly reported data on cases of COVID-19 in ‘other residential care settings’.

157. The Australian Government in its submissions noted that it was addressing gaps in data reporting by proposing that the Australian Institute of Health and Welfare create a COVID-19 registry and linked dataset. 238 According to the Australian Government’s submissions, the proposed dataset:

will be a registry of people with a positive diagnosis of COVID-19 as reported to state and territory communicable disease units and on to the NNDSS. When linked with other data such as mortality, aged

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234 Exhibit 5.42, Statement of Simon Cotterell, 10 August 2020, at [23].
235 Exhibit 5.42, Statement of Simon Cotterell, 10 August 2020, at [23]; Exhibit 5-5.08, DRC.2000.0002.0001.
236 Exhibit 5.42, Statement of Simon Cotterell, 10 August 2020, at [24].
237 Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P-314 [24-26]. The CDNA guidelines note that a residential care facility can be ‘any public or private service where residents are provided with personal care or health care by facility staff’. The guidelines include a list of five types of facilities, one of which is ‘residential aged care facility’. It can be inferred that ‘other residential care facility’ comprises: residential physical or mental disability care; community based residential health facilities (for example, drug and alcohol services); long stay hospital wards and rehabilitation hospitals; and other similar accommodation settings in Australia. See Exhibit 5-96, DRC.2000.0002.1578.
238 Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [74].
care and other vulnerable groups, [Medical Benefits Schedule], PBS and hospitals data, the registry will be a robust asset for use in COVID-19 research and monitoring. The COVID-19 linked dataset would aim to respond to the emerging medium and longer-term data needs of the COVID-19 pandemic in Australia’s Infection and mortality rate data.239

158. It is not clear from the Australian Government’s submissions whether the Australian Institute of Health and Welfare registry is intended to include a disability identifier that would allow people with disability to be identified. Without such an identifier, it is not possible to disaggregate by disability status (that is, to report the numbers of people with disability who have tested positive for COVID-19). This would seem to mean that the data collated in the registry will be of limited utility in informing decision-making about ‘appropriate actions’, as the COVID-19 Plan (and the CRPD) envisage. The risk is that decision-making will continue to overlook or minimise the true impact of COVID-19 on people with disability.

159. We accept that the Australian Government must cooperate with the states and territories, given their role in data collection, data management and data reporting.240 For the reasons we have given,241 however, we do not accept that the Australian Government can satisfy its obligations to comply with article 31 of the CRPD by asserting that it does not have direct responsibility for data collection concerning COVID-19 and that it relies on the states and territories. While it is open to the Australian Government to involve the states and territories in discharging its obligations, that does not relieve the Australian Government of its responsibility to ensure that appropriate data is collected, disseminated and readily accessible.

239 Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [74].
240 Submission of Counsel Assisting, Public hearing 5, 4 September 2020, DRC.9999.0019.0001 at [376]; Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [81-82].
241 Report, [147-149].
Findings and recommendations

160. We make the following findings:

160.1 The Australian Government Department of Health has not collected data about how many people with disability have contracted COVID-19 since the onset of the pandemic in January 2020.

160.2 Data about infections and deaths in disability accommodation under the ‘other residential care facility setting’, which was first collected at a late stage of the pandemic, should have been disseminated, but has not been published as of 4 November 2020.

160.3 Because of the deficiencies in the collection and dissemination of data, it is not possible to obtain a complete or accurate picture of the infection and mortality rates from COVID-19 for people with disability throughout Australia.

160.4 The failure to collect and disseminate national data on the rates of infection and death from COVID-19 for people with disability is inconsistent with Australia’s obligations under article 31 of the Convention on the Rights of Persons with Disabilities.

Recommendation 14:

The Australian Government should immediately introduce measures to ensure that it complies with its obligations under article 31 of the United Nations Convention on the Rights of Persons with Disabilities. For this purpose:

14.1 The Australian Government should ensure that the proposed COVID-19 registry disaggregates data by disability status and by reference to people in ‘residential disability care facilities’.
14.2 The Australian Government Department of Health should publish statistics at least weekly on the number of confirmed active COVID-19 cases, deaths and recovered cases in Australia for each state and territory for people living in ‘residential disability care facilities’.

14.3 The Australian Government Department of Health in coordination with the NDIS Quality and Safeguards Commission should publish statistics at least weekly on the number of confirmed active COVID-19 cases, deaths and recovered cases among National Disability Insurance Scheme participants in Australia and in each state and territory.

NDIS Quality and Safeguards Commission (NDIS Commission) and National Disability Insurance Agency (NDIA)

161. The Royal Commission’s Statement of Concern issued on 26 March 2020 expressly identified interruptions to essential support services and reduced oversight in closed residential settings during the COVID-19 pandemic as presenting threats to people with disability. The Statement of Concern called on governments to develop a strategy that, among other things, ensured that:

- people with disability had access to essential services, including assistance with toileting, showering, sleeping and getting dressed
- all necessary measures were taken to reduce the risk of infection in closed congregate settings
- measures were in place to reduce the risk of infection by ensuring that support workers were properly trained, including in infection control.
162. We noted that measures to ‘lockdown’ facilities or restrict visits might have the unintended consequence of limiting the effectiveness of both formal oversight mechanisms such as Community Visitor Schemes, and informal oversight by family, friends, supporters and advocates.

163. These difficulties affected and continue to affect many people with disability. The principal Australian Government agencies responsible for protecting the safety, health and wellbeing of NDIS participants are the NDIS Commission and the NDIA.

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**Xanthe***

In a response to the Emergency Planning and Responses Issues Paper, Xanthe described how at the beginning of April, a service provider who operates supported accommodation where her family member lives ceased ‘all visitation from family, including mothers engaging their children in essential care tasks and essential exercise, without consultation’. Xanthe considered this created a risk to residents of the supported accommodation because it removed the informal oversight that visitors provide. She said that usually,

… families are the ones picking up on illness and injury where [a person with disability] cannot speak for themselves. They’re the ones spotting that stuff hasn’t been done or cleaned or actioned.

Xanthe said that at the time of the decision to lock down the supported accommodation, there were no known or suspected COVID-19 cases at the service. She said the lockdown was not necessary under state or federal health directives and the decision to lockdown failed to take into account residents’ personal circumstances. She also said the service provider failed to support residents to adapt to the lockdown by enabling them to use Skype in lieu of face to face meetings or to use treadmills instead of going on walks.

* Name has been changed and some details removed to protect people’s identities. This narrative is based on a response received by the Royal Commission to the Emergency Planning and Responses Issues Paper. Note that the response and this narrative did not form any part of the evidence at the public hearing discussed in this report.
NDIS Commission

164. The function of the NDIS Commission is to assist the NDIS Commissioner in the performance of his or her functions. The Commissioner’s functions include the ‘core functions’. Since the NDIS Commission consists of the Commissioner and the staff of the NDIS Commission, for present purposes it is generally not necessary to distinguish between the NDIS Commission and the Commissioner. We therefore refer simply to the NDIS Commission except where the context requires otherwise.

165. The NDIS Commissioner’s core functions include the following:

(a) to uphold the rights of, and promote the health, safety and wellbeing of, people with disability receiving supports or services including those received under the National Disability Insurance Scheme

(b) to develop a nationally consistent approach to managing quality and safeguards for people with disability receiving supports or services, including those received under the [NDIS]

(c) to promote the provision of advice, information, education and training to NDIS providers and people with disability and

(d) to secure compliance with this Act through effective compliance and enforcement arrangements, including through the monitoring and investigation functions conferred on the Commissioner.

[Emphasis added]

166. Chapter 6A of the National Disability Insurance Scheme Act 2013 (Cth) (NDIS Act) specifies the NDIS Commissioner’s registration and reportable incident functions, the complaints functions and the

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242 National Disability Insurance Act 2013 (Cth) s 181B. Section 181B is in Chapter 6A of the National Disability Insurance Act 2013 (Cth) (ss 181A-181Y).
244 National Disability Insurance Act 2013 (Cth) s 181A(3).
245 See Alan Robertson SC, Independent review of the adequacy of the regulation of supports and services provided to Ms Ann-Marie Smith, an NDIS participant, who died on 6 April 2020, Report to the Commissioner of the NDIS Quality and Safeguards Commission, 31 August 2020, pp 28-29.
246 National Disability Insurance Act 2013 (Cth) ss 181E(a)-(d).
behaviour support functions.\textsuperscript{247} The NDIS Commissioner also has power to do all things necessary or convenient to be done for or in connection with the performance of his or her functions.\textsuperscript{248}

167. The expression ‘supports’, which is used in the NDIS Act, is defined to include ‘general supports’.\textsuperscript{249} ‘General support’ means:

(a) a service provided by the [NDIA] to a person; or

(b) an activity engaged in by the [NDIA] in relation to a person, that is in the nature of a co-ordination, strategic or referral service.\textsuperscript{250}

168. The first two ‘core functions’ of the NDIS Commissioner, set out in sections 181E(a) and (b), refer to supports or services ‘including those received under the [NDIS]’. This language suggests that the NDIS Commissioner’s core functions may extend to supports or services received by people with disability who are not NDIS participants. Three other core functions of the NDIS Commissioner, including section 181E(c) extracted above, refer to ‘people with disability’, not ‘NDIS participants’ and therefore appear to be similarly unrestricted.\textsuperscript{251} It is not necessary for present purposes to express a concluded view on this question of statutory interpretation, but it may warrant further consideration later in our work.

169. The NDIS Commission recognised at an early stage that the COVID-19 pandemic presented a significant risk to NDIS participants and providers.\textsuperscript{252} It regarded service providers as bearing primary responsibility to identify and manage the risk. The NDIS Commission saw its role, in this context, as communicating with service providers, who would then be responsible for heeding and acting on the advice.

\textsuperscript{247} National Disability Insurance Act 2013 (Cth) ss 181E, 181F, 181G.
\textsuperscript{248} National Disability Insurance Act 2013 (Cth) s 181D(5).
\textsuperscript{249} National Disability Insurance Act 2013 (Cth) s 9.
\textsuperscript{250} National Disability Insurance Act 2013 (Cth) s 13(2).
\textsuperscript{251} National Disability Insurance Act 2013 (Cth) ss 181E(c), (e) and (f).
\textsuperscript{252} Exhibit 5.46, Statement of Graeme Head, 13 August 2020, at [8]. See also, Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [42].
Ms Taylor, Registrar of the NDIS Commission, explained in her witness statement that:

I have generally considered it important throughout this period that the responsibility for determining the risk factors affecting the health, safety and wellbeing of participants must be determined by the providers themselves, given the diversity of the NDIS market and the plethora of support arrangements in the NDIS.  

170. We have referred to the NDIS Commission’s first and second ‘Provider Alerts’, issued respectively on 7 February and 9 March 2020. The first Provider Alert did not advise that any specific action should be taken in response to the risks posed by COVID-19. The second Provider Alert set out provider obligations in managing the increased risk of infection of NDIS participants during the pandemic, reminded providers of the conditions of registration that they notify the NDIS Commission of certain changes or events and contained information from the Department of Health about the risks of COVID-19.

171. The Provider Alerts were followed by a letter on 24 March 2020 requiring service providers to notify the NDIS Commission of any changes or events impairing their ability to deliver ongoing supports. They were also required to inform the NDIS Commission of confirmed COVID-19 infections of NDIS participants or workers by way of a notification form. By 13 August 2020, the NDIS Commission had been notified of 124 worker COVID-19 infections and 76 participant COVID-19 infections. As at that date, the NDIS Commission had conducted three investigations into the confirmed infections which, as

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253 Exhibit 5.48, Statement of Samantha Taylor, 12 August 2020, at [111].
254 Report, [47], [55].
255 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [46]; Exhibit 5.183, CTD.7200.0001.3449.
Ms Taylor explained, related to multiple (that is, more than three) individuals.\textsuperscript{256}

172. The NDIS Commission continued to issue Provider Alerts to NDIS providers. The NDIS Commission also published some information for the benefit of NDIS participants.\textsuperscript{257} However, it was not until 13 May 2020 that the NDIS Commission issued a fact sheet on COVID-19 outbreak preparedness, prevention and management.\textsuperscript{258} This was more than three months after the first Provider Alert.

173. Ms Taylor said that ‘nothing has changed in the course of the pandemic in terms of how provider obligations must be met under the NDIS Code’.\textsuperscript{259} Mr Graeme Head AO, the NDIS Commissioner, also gave evidence that registered NDIS providers’ obligations under the NDIS Practice Standards\textsuperscript{260} and \textit{National Disability Insurance Scheme (Quality Indicators) Guidelines 2018 (NDIS Quality Indicators)} had not changed.\textsuperscript{261} However, Ms Taylor explained that the NDIS Commission did make changes to the process of registration renewals and audits, including advising approved auditors to delay or reschedule audit dates where providers could not proceed with an audit.\textsuperscript{262} The NDIS Commission also allowed additional time for registered NDIS providers to complete the registration renewal process, including the audit.\textsuperscript{263}

174. The NDIS Commission’s reliance on service providers to manage risk in the event of an outbreak was stated plainly in the Australian Government’s submissions:

\footnotesize{\textsuperscript{256} Transcript, Samantha Taylor, Public hearing 5, 21 August 2020, P-389 [7-12]. See also, Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [163].
\textsuperscript{257} Exhibit 5.189, CTD.7200.0001.3348; Exhibit 5.196, CTD.7200.0001.3399.
\textsuperscript{258} Exhibit 5.199, CTD.7200.0001.3330.
\textsuperscript{259} Transcript, Samantha Taylor, Public hearing 5, 21 August 2020, P-384 [37-38].
\textsuperscript{260} Exhibit 5.233, DRC.2000.0002.1474.
\textsuperscript{261} Exhibit 5.46 Statement of Graeme Head AO, 13 August 2020, at [21].
\textsuperscript{262} Exhibit 5.48, Statement of Samantha Taylor, 12 August 2020, at [48].
\textsuperscript{263} Exhibit 5.48, Statement of Samantha Taylor, 12 August 2020, at [49].}
It is the responsibility of providers to determine the risk factors in relation to continuing to provide supports and services in any circumstance, including the COVID-19 pandemic, and including as required under the NDIS Practice Standards. The NDIS Commission considers, as between the NDIS Commission and providers, that providers have primary responsibility for participants in the event of an outbreak and that the NDIS Commission should not be responsible for issuing advice to providers about when infection control nurses should be engaged. If such advice is required, it should be obtained from state or territory local public health authorities.264

175. The NDIS Commission expected that providers should have been prepared for the COVID-19 pandemic from the outset. The Australian Government’s submissions contended that service providers should not have come into the COVID-19 pandemic without plans in place for infection control and management of outbreaks. This followed, so it was argued, from existing requirements for service providers to identify, analyse, prioritise and treat risks.265 The evidence of service providers at the hearing was that they did not have pandemic plans in place prior to COVID-19 arriving in Australia.266

176. Until relatively recently, the NDIS Commission did not consider it necessary to amend the NDIS Practice Standards in response to the COVID-19 pandemic. Mr Head said that the NDIS Practice Standards were framed sufficiently broadly to cover service providers’ responsibilities during the pandemic,267 but that statement was later qualified. Ms Taylor said that in early July 2020 she informed Mr Head that she considered there was an opportunity ‘to strengthen and

264 Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [161]. See also, [158].
266 Exhibit 5.255, Statement of Claire Robbs, 14 August 2020, at [155]; Exhibit 5.250, Statement of Andrew Richardson, 16 August 2020, at [133].
267 Exhibit 5.46, Statement of Graeme Head AO, 13 August 2020, at [22]; Supplementary statement of Graeme Head AO, 27 August 2020, at [39].
clarify the NDIS Practice Standards and NDIS Quality Indicators. Mr Head said that he expected the proposal to clarify the obligations of registered NDIS providers in relation to infection control and related issues.

177. The NDIS Commission was asked whether it had taken specific action to increase oversight of closed residential settings in response to the increased isolation of people with disability due to COVID-19. In her witness statement, Ms Taylor said that the NDIS Commission had taken steps in relation to all settings and had introduced specific notification requirements for COVID-19 (described at paragraph 168 above). She also said that the NDIS Commission had continuing quality and safeguarding functions, including the capacity to carry out investigations, and that it had undertaken some investigations.

Ms Taylor also said that she referred regulatory arrangements for closed residential settings to the NDIS Commission’s Disability Sector Consultative Committee. This Committee met on 30 June 2020 and discussed ways to facilitate advocates providing information and to support the dissemination of NDIS Commission information to people with disability through member networks. She added that it was:

not yet clear … whether participants have experienced higher rates of violence, abuse, neglect and exploitation during the pandemic to date, or whether rates of violence, abuse, neglect and exploitation have increased in connection with the provision of NDIS supports and services or in other settings, such as in circumstances of family violence. I have not seen evidence of an increase in the information available to the NDIS Commission to date, although I am alive to

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268 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [131].
269 Exhibit 5.46, Statement of Graeme Head AO, 13 August 2020, at [39]; Supplementary statement of Graeme Head AO, 27 August 2020, at [40].
271 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [87-88].
272 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [90-91].
the possibility that this might reflect some decrease in opportunities to report or complain.  

Ms Taylor said that this was a matter that the NDIS Commission would ‘keep under review’.  

**A more active role?**  

178. The NDIS Commission’s view that service providers have primary responsibility to identify and manage risks to NDIS participants during the pandemic may have rested, at least in part, on its interpretation of its statutory functions. We do not agree that the terms of the NDIS Act precluded the NDIS Commission from taking a more active role in protecting the safety, health and wellbeing of NDIS participants during the COVID-19 pandemic.  

179. The core functions of the NDIS Commissioner in section 181E of the NDIS Act are expressed very widely. They include upholding the rights of and promoting the health, safety and wellbeing of NDIS participants. An emergency such as a pandemic plainly presents an immediate and ongoing threat to the safety, health and wellbeing of NDIS participants, as was accepted by the NDIS Commission. In these circumstances the plain language of the NDIS Act would seem to provide ample authority for the NDIS Commission to take active measures itself to protect and preserve the safety, health and wellbeing of NDIS participants. In short the NDIS Commission is not restricted to relying primarily on service providers to manage the risks facing NDIS participants during a pandemic. Nor is the NDIS Commissioner restricted by the governing statute to providing advice and information to service providers and NDIS participants (although the provision of advice, information, education and training to NDIS providers and people with disability is one of the NDIS Commissioner’s core functions).  

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273 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [93].  
274 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [93].  
275 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [18].  
276 *National Disability Insurance Act 2013 (Cth)* s 181E(c).
180. A number of witnesses commented that the arrangements in place at the onset of the pandemic did not adequately address the unprecedented circumstances in which service providers and NDIS participants found themselves. Professor Michelle Villeneuve, an Associate Professor in the Faculty of Medicine and Health at the University of Sydney, explained that the NDIS Quality and Safeguarding Framework:

> provides a nationally consistent approach to help empower and support NDIS participants to exercise choice and control, while ensuring appropriate safeguards are in place. **It establishes expectations for providers and their staff to deliver high quality supports and clarifies how providers should respond during a “serious incident”**,277 However, the NDIS Quality and Safeguarding Framework does not explicitly address natural hazard disaster risk (no house fire, nor pandemic). There are no provisions for emergency preparedness of people with disability and the services that support them in this definition.278 [Emphasis in original]

181. Professor Kavanagh expressed the view that the NDIS Commission should have been more directive about whether service providers should continue to provide services and supports safely to NDIS participants.279 She pointed out that NDIS service providers have a financial incentive to stay open in a precarious economic environment.280 In her opinion, it was not reasonable to expect people holding management positions in service providers, who are not public health experts, to determine whether or not services and supports could be provided safely to NDIS participants. Professor Kavanagh considered that both the NDIA and the NDIS Commission could have taken ‘a more proactive approach’ by giving clearer directions about how service providers could deliver different kinds of

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277 Defined as events that disrupt service provision or threaten the safety of people or property.
278 Exhibit 5.24, Statement of Michelle Villeneuve, 31 July 2020, at [69].
279 Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [103-117].
280 Transcript, Anne Kavanagh, Public hearing 5, 20 August 2020, P-215 [7-8].
supports during the pandemic and how they could reach out to alternative providers if they were unable to operate safely.  

182. Professor Kavanagh also noted that neither the NDIS Commission nor the NDIA has a ‘background in public health’. She recommended that the NDIS Commission and the NDIA should rapidly scale up capacity in relation to a public health response and should also work closely with people in public health in the Australian Government, states and territories.

183. The Australian Government rejects any suggestion that the NDIS Commission should have issued directives going beyond providing information and advice to service providers. Specifically, the Australian Government submits that the NDIS Commission does not have power to direct a registered NDIS provider not to provide supports, otherwise than by suspending or revoking the registration of the provider for cause. The Australian Government points to the role of the states and territories in issuing health orders and providing health advice. It also says the NDIS Commission has to take account of the wide variety of circumstances in which supports are provided and the importance of the NDIS respecting the choices of participants and of health workers. The Australian Government acknowledges that delaying conduct of audits increases the risk of non-compliance with registration requirements, but says that the NDIS Commission is comfortable with its approach to date and is keeping the matter under review.

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281 Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [55].
282 Transcript, Anne Kavanagh, Public hearing 5, 20 August 2020, P-216 [1-2].
284 Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [157]. The power to suspend or revoke the registration of a provider is conferred by ss 73N and 73P of the National Disability Insurance Act 2013 (Cth).
286 Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [208]. See also, Exhibit 5.48, Statement of Samantha Taylor, 12 August 2020, at [50].
184. In our view, the Australian Government takes an unduly narrow view of the actions that were open to the NDIS Commission once the potential scale of the pandemic and the threats to NDIS participants became apparent. The NDIS Commission has power at any time to impose conditions on the registration of service providers.\textsuperscript{287} The conditions, among other things, can include:

Requirements relating to supports or services for which the provider is registered to provide, including circumstances in which supports or services for which the provider is registered can or cannot be provided.\textsuperscript{288}

185. If the NDIS Commission needed additional powers to take a more active role in ensuring that the risks to NDIS participants were minimised it could have made an urgent request to the Minister to issue new NDIS Practice Standards.\textsuperscript{289} The legislation states that Practice Standards may relate to the quality of supports or services to be provided by registered NDIS providers and the way standards are to be complied with by providers if they are to remain registered.\textsuperscript{290}

186. We accept that at the onset of the pandemic the NDIS Commission expected registered service providers to manage the risks to which NDIS participants were exposed. We also accept that the NDIS Practice Standards addressed in general terms the approach that service providers should take to managing those risks. But the potential scale and impact of the pandemic created a situation that was fundamentally different and more dangerous than anything that service providers previously had to deal with.

187. It was clear from early in the pandemic – and appreciated by the NDIS Commission – that many NDIS participants would be exposed to the risk of infection and the sudden loss of or interruption to

\textsuperscript{287} National Disability Insurance Act 2013 (Cth) ss 73G(1), (2).
\textsuperscript{288} National Disability Insurance Act 2013 (Cth) s 73G(3)(c).
\textsuperscript{289} National Disability Insurance Act 2013 (Cth) ss 73T(1), 209.
\textsuperscript{290} National Disability Insurance Act 2013 (Cth) s 73T(3)(b).
essential support services. It was foreseeable that NDIS participants were likely to face an increased risk of abuse and neglect in circumstances where formal and informal oversight mechanisms either diminished in effectiveness or ceased to operate. The NDIS Commission was also aware that many service providers were new to the NDIS and had little experience in providing services to NDIS participants. They therefore had to adapt to an extraordinarily challenging environment without the benefit of experience in infection control.

188. In our view, it was not appropriate for the NDIS Commission to rely on existing Practice Standards and policies to address the challenges and danger presented by the onset of a frightening pandemic, particularly where audits against those existing Practice Standards were sometimes postponed. It was not a sufficient response to issue advice and information to registered service providers. Nor was it appropriate to assume that existing mechanisms such as complaints procedures would protect NDIS participants from the unprecedented risk of harm they faced.

189. We appreciate that as Ms Taylor explained, the NDIS Commission has made some ‘operational changes’ over the course of the pandemic. We note also that the NDIS Commission has sought to obtain information in relation to COVID-19 infections notified to it, although its actions appear to be rather limited. We also note that a number of matters relating to COVID-19 were referred to the NDIS Commission’s compliance team. And of course we accept that the NDIS Commission did not and does not have unlimited resources. Nonetheless we consider that the NDIS Commission should have

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291 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [18], [20], [61], [78-79].
292 Transcript, Graeme Head, Public hearing 5, 21 August 2020, P-387 [20-30].
293 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [54-55].
295 Exhibit 5.48, Statement of Samantha Taylor, 13 August 2020, at [62].
intervened more actively from the onset of the pandemic to ensure, so far as feasible, the safety, health and wellbeing of NDIS participants.

190. The interventions at least should have been directed to determining which NDIS participants were at particular risk and to ascertaining whether service providers were taking the appropriate measures to reduce the risk of infection to both NDIS participants and support staff and to provide continuity of essential supports. The interventions should also have been directed to monitoring whether support staff were being adequately trained in infection control.296

191. The NDIS Commission persisted with its reliance on service providers for dealing with failures of support and infection control, notwithstanding that circumstances had changed radically with the advent of the pandemic. This represented a lost opportunity for the regulator to utilise its power and authority to the maximum extent in an emergency.

192. We agree with the Honourable Alan Robertson SC who recommended in his report on the tragic death of Ms Ann-Marie Smith that the NDIS Commission:

   should act to identify earlier those people with disability who are vulnerable to harm or neglect. Every stage of decision-making should be alive to factors indicating that a participant may be vulnerable to harm or neglect.297

296 We comment at [193-195] below about the NDIA’s outreach program to NDIS participants.
297 Alan Robertson SC, Independent review of the adequacy of the regulation of supports and services provided to Ms Ann-Marie Smith, an NDIS participant, who died on 6 April 2020, Report to the Commissioner of the NDIS Quality and Safeguards Commission, 31 August 2020, p. 68.
Findings and recommendations

193. We make the following findings:

193.1 From the onset of the COVID-19 pandemic the NDIS Quality and Safeguards Commission adhered to its policy of placing responsibility on registered service providers to determine the risk factors affecting National Disability Insurance Scheme participants and to ensure their safety, health and wellbeing. The NDIS Quality and Safeguards Commission followed this course notwithstanding that circumstances had changed radically and the risks to National Disability Insurance Scheme participants had increased substantially.

193.2 The National Disability Insurance Scheme Act 2013 (Cth) did not preclude the NDIS Quality and Safeguards Commission from adopting a more active approach during the COVID-19 pandemic. If the NDIS Quality and Safeguards Commission believed that a more active role was outside its statutory functions, that belief was based on an unduly narrow interpretation of the legislation.

193.3 The NDIS Quality and Safeguards Commission did not take specific steps to intensify active oversight of National Disability Insurance Scheme participants living in closed residential settings in response to the isolation they experienced due to the COVID-19 pandemic.

193.4 While we are unable to conclude on the evidence that a more active approach would have prevented COVID-19 infections and deaths among National Disability Insurance Scheme participants and support staff, the decision to maintain existing policies and practices represented a lost opportunity to protect and safeguard the safety, health and wellbeing of National Disability Insurance Scheme participants.
Recommendation 15:

The NDIS Quality and Safeguards Commissioner should review the National Disability Insurance Scheme Practice Standards and National Disability Insurance Scheme Quality Indicators to ensure that they are appropriate for pandemics and other emergencies. The review should be informed by the views of people with expertise in public health emergencies including pandemics and outbreaks of infectious diseases.

Recommendation 16:

The NDIS Quality and Safeguards Commissioner’s policies, procedures and practices should reflect its powers and responsibilities to take active measures to protect and preserve the safety, health and wellbeing of National Disability Insurance Scheme participants during an emergency such as a pandemic.

194. The Royal Commission will investigate in future hearings and public engagements the role that the NDIS Commission should play in identifying and protecting people with disability who are particularly at risk of violence, abuse, neglect or exploitation.

NDIA

195. A number of issues were raised at the hearing about the role of the NDIA during the pandemic. The major questions related to the NDIA’s outreach program to ‘vulnerable’ participants and its approach to plan flexibility during the pandemic. We refer only briefly to the evidence bearing on these questions and we do not make any findings or recommendations concerning the NDIA. Mr Martin Hoffman, the CEO of the NDIA, provided a written statement to the Royal Commission but he was not asked to give oral evidence. We shall examine the role of the NDIA in our future work.
Outreach program

196. In early April 2020, the NDIA began:

proactively reaching out to 62,188 NDIS participants who were [considered] at greater risk due to COVID-19 to ensure they continued to receive and access their essential disability supports.298

From 6 April 2020 until 30 June 2020, a total of 73,324 outreach calls were made.299 Following the extension of stage 3 restrictions in Victoria on 2 July 2020, the NDIA recommenced outbound calls to NDIS participants living in metropolitan Melbourne and the Mitchell Shire in central Victoria.300

197. Mr Hoffman said that NDIS participants were asked how they were managing and whether they had access to the supports they required. The callers also checked participants’ use of plans and their funding levels to ascertain whether they had sufficient flexibility and whether a plan review would be appropriate.301 If the NDIA had concerns about the wellbeing of a participant living in stage 4 restricted regions, the Local Area Coordinator would seek to visit the participant. Occasionally the concerns were referred to local police to undertake a welfare check.302 However, the NDIA did not arrange for the provision of PPE as part of the outreach program.303

198. Professor Kavanagh considered that the outreach calls were a missed opportunity. In her view, if the NDIA had been advised by public health experts the program might have been more targeted and effective. For example, the NDIA might have ascertained whether participants and their families had access to information on infection control and whether they needed PPE. The calls also might have

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298 Exhibit 5.45A, Statement of Martin Hoffman, 25 September 2020, at [14].
299 Exhibit 5.45A, Statement of Martin Hoffman, 25 September 2020, at [14].
300 Exhibit 5.45A, Statement of Martin Hoffman, 25 September 2020, at [16].
301 Exhibit 5.45A, Statement of Martin Hoffman, 25 September 2020, at [21].
302 Exhibit 5.45A, Statement of Martin Hoffman, 25 September 2020, at [21].
303 Exhibit 5.45A, Statement of Martin Hoffman, 25 September 2020, at [25].
provided an opportunity to determine whether the services provided to NDIS participants should be modified or new services put in place.\textsuperscript{304}

**NDIS plan flexibility**

199. We heard evidence about NDIS participants seeking to adjust their NDIS plans to meet additional needs arising during the COVID-19 pandemic. Ms Deane, Campaign Director of Every Australian Counts, gave evidence about a survey of NDIS participants and their family members conducted during the first lockdown in Victoria. Ms Deane said that many respondents to the survey were:

- frustrated by confusing and inconsistent information, an inability to use their funds in a way that worked for them and lack of support in trying to navigate the changes the pandemic had made to their lives.\textsuperscript{305}

200. Ms Deane reported that people were also often frustrated and confused about how the NDIA communicated changes to the funding of assistive technology supports.\textsuperscript{306}

201. The Royal Commission’s statement of concern called on governments to develop strategies to ensure, as far as possible, that people with disability would not be forced to accept help from support workers, family members or friends who were themselves unwell. Some witnesses expressed concern that NDIS participants could not use NDIS funds to pay family members who were providing essential support services during the pandemic.\textsuperscript{307} Ms Sheree Driver, for example described her sister’s experience of contracting COVID-19 from a support worker. Ms Driver emphasised the importance of flexibility to allow a participant’s individual needs and circumstances

\textsuperscript{304} Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [129-130].
\textsuperscript{305} Exhibit 5.26, Statement of Kirsten Deane, 12 August 2020, at [44].
\textsuperscript{306} Transcript, Kirsten Deane, Public hearing 5, 19 August 2020, P-142 [31-36].
\textsuperscript{307} See for example, Transcript, AAV, Public hearing 5, 18 August 2020, P-46 [40-47], P-47 [1-9], P-48 [20-30]; Transcript, Sheree Driver, Public hearing 5, 19 August 2020, P-117 [26-40].
to be taken into account during the pandemic.\textsuperscript{308} Professor Kavanagh proposed that the capacity of the NDIA to be able to make rapid adjustments to funding to individual plans should be ‘significantly enhanced’.\textsuperscript{309}

202. Mr Hoffman said that requests to enable family members of NDIS participants to be paid as support workers increased during the COVID-19 pandemic, although the NDIA did not record the precise number.\textsuperscript{310} He stated that on 2 September 2020 the NDIA introduced a temporary and time-limited policy to permit NDIS participants testing positive to COVID-19 to pay family members to provide supports where other funded supports are unavailable.\textsuperscript{311} Mr Hoffman advised in his supplementary statement that by 25 September 2020 the NDIA had approved approximately six requests for family members to be paid as support workers for NDIS participants during the COVID-19 pandemic.\textsuperscript{312}

203. Ms Ricky Buchanan gave evidence about her own disaster plan, which she created using the Person Centred Emergency Preparedness resources.\textsuperscript{313} There may be potential to adopt this kind of innovative approach to individual emergency and pandemic planning more widely, for example when NDIS participants review their plans with the NDIA.

204. We make the following observations:

- First, a person-centred approach, which respects the rights of people with disability to exercise choice and control and which protects against the risk of abuse and neglect, is essential during a pandemic just as it is at other times. Such an approach requires flexibility and speed in the administration of

\textsuperscript{308} Exhibit 5.4, Statement of Sheree Driver, 12 August 2020; Transcript, Sheree Driver, Public hearing 5, 19 August 2020, P-119 [19-30].
\textsuperscript{309} Exhibit 5.30, Statement of Anne Kavanagh, 20 August 2020, at [167].
\textsuperscript{310} Exhibit 5.45A, Statement of Martin Hoffman, 25 September 2020, at [50].
\textsuperscript{311} Exhibit 5.45A, Statement of Martin Hoffman, 25 September 2020, at [51].
\textsuperscript{312} Exhibit 5.45A, Statement of Martin Hoffman, 25 September 2020, at [53].
\textsuperscript{313} Exhibit 5.3, Statement of Ricky Buchanan, 4 August 2020, at [10-11].
plans. There seems to be a strong case for NDIS participants being able to use their funds flexibly in order to stay safe and as well as possible during a pandemic.

- Second, there is potential for innovative approaches to be considered in the course of planning processes involving NDIS participants during emergencies, such as pandemics.

- Third, it was the NDIA, not the NDIS Commission, that made direct contact with NDIS participants during the COVID-19 pandemic. The respective roles of the NDIA and NDIS Commission are matters to which the Royal Commission will return in the future.\(^\text{314}\)

\(^{314}\) This is also a matter addressed by the Alan Robertson SC, *Independent review of the adequacy of the regulation of supports and services provided to Ms Ann-Marie Smith, an NDIS participant, who died on 6 April 2020*, Report to the Commissioner of the NDIS Quality and Safeguards Commission, 31 August 2020.
Charlee and Fisher*

Charlee is in her late thirties and has an intellectual disability. Until recently, she lived in the same home for four years. Her father, Fisher, told us she has always been ‘very happy and stable’.

Charlee’s parents are in their seventies.

At the end of March 2020, Fisher received an unexpected email from the CEO of Charlee’s group home provider stating that Charlee couldn’t return to the home after a weekend stay with her family.

The CEO’s email said that Charlee didn’t understand how to socially distance from other residents and staff, and was unable to thoroughly wash her hands. Fisher told us Charlee needs the same assistance as a pre-schooler and her carers were aware of her needs. However, he agreed to keep her home, thinking it would be for a limited time.

The situation escalated when Fisher received another email in May, providing one month’s notice of the termination of Charlee’s service agreement. Charlee had still not returned to the group home at this time. The email said the decision to terminate was made ‘in light of the COVID-19 pandemic restrictions’. It also suggested that Charlee received extra support from her carers to the detriment of the other residents.

The service provider refused to let Charlee say goodbye to the carers or other residents who had become her friends. Fisher said the sudden termination devastated Charlee, causing long-term stress and a 10-day episode of ‘anxiety-related catatonia’. Fisher said Charlee has not responded well to the significant disruption to her lifestyle, including no contact with her housemates and her carers.

* Names changed and some details removed to protect people’s identities. Narrative based on a submission to the Royal Commission. Note that the submission and this narrative did not form any part of the evidence at the public hearing discussed in this report.
Disability workforce

205. As noted in paragraph 47 above, the University of New South Wales Social Policy Research Centre released a report entitled *The disability workforce and COVID-19: initial experiences of the outbreak* on 21 April 2020.\(^{315}\) The report, which was prepared for three unions,\(^{316}\) drew on data from a survey of 2,341 disability workers conducted in March 2020.\(^{317}\) The key findings of the survey were:

- PPE was not supplied to staff and clients
- many workers felt that their organisation’s safety protocols were inadequate to deal with COVID-19
- a widespread belief that the disability workforce had been dangerously overlooked in the responses to the pandemic
- the respondents held concerns about day programs and community access activities remaining in operation
- disability workers were often unable to self-isolate and suffered financially if they did so.\(^{318}\)

206. On 31 July 2020, the Disability and Health Unit of the University of Melbourne published *Disability Support Workers: The forgotten workforce in COVID-19* (*Forgotten workforce*).\(^{319}\) The report was based on an online survey of 357 disability support workers across Australia conducted in June 2020. The survey findings included:\(^{320}\)

- 90 per cent of respondents said they were not able to maintain physical distancing at work

\(^{315}\) Exhibit 5.58, DRC.2000.0003.0395.
\(^{316}\) The Health Services Union, the Australian Services Union and the United Workers Union.
\(^{317}\) Exhibit 5.58, DRC.2000.0003.0395 at 0398.
\(^{318}\) Exhibit 5.58, DRC.2000.0003.0395 at 0398.
\(^{319}\) Exhibit 5.30.12, EXP.0031.0001.0094.
\(^{320}\) Exhibit 5.30.12, EXP.0031.0001.0094 at 0097.
• 53 per cent were required to provide support services involving close personal contact, such as feeding or brushing the teeth of a person with disability

• 23 per cent had not received any COVID-19 infection control training and, of those, 69 per cent wanted more training

• of the 77 per cent of respondents who had received training, 48 per cent would have liked more training.  

Casualisation of the disability workforce

207. Professor Kavanagh gave evidence about the preparedness of the disability workforce during COVID-19. She said that the disability workforce is a ‘highly transient and casualised workforce’, which creates risk factors for people with disability. She observed that casual workers in the disability sector are poorly paid and have a greater incentive than better paid workers to attend work when they are sick or have symptoms.

208. Ms Claire Robbs, CEO of Life Without Barriers, referred to the challenge of balancing flexibility of staffing with continuity of care to people with disability. She pointed out that in cases of suspected infection, up to 12 staff members may have to be isolated, creating the need to rely on casual staff. Ms Robbs stated that more than 30 per cent of Life Without Barriers’ staff are casuals and that the turnover rate of casual staff is about 40 per cent per annum. However, Ms Robbs also said that permanent staff accounted for 85 per cent of hours worked. Therefore, while the proportion of casual workers appears to be relatively high ‘they don’t represent a large percentage of the hours worked across our group living program’. Nonetheless, Life Without Barriers sought to minimise the risks associated with

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321 Exhibit 5.30.12, EXP.0031.0001.0094 at 0097.
322 Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [132-145].
323 Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [140].
324 Transcript, Claire Robbs, Public hearing 5, 20 August 2020, P-294 [40-48].
325 Transcript, Claire Robbs, Public hearing 5, 20 August 2020, P-303 [36-40].
casual staff by limiting the number of places at which each casual member of staff can work.

209. According to Mr Andrew Richardson, CEO of Aruma, 26 per cent of Aruma’s staff are casual and the turnover rate of casual staff is 32 per cent per annum. However, he also noted that Aruma had recently taken over some services previously administered by the Victorian state government and the employees of those services would remain Victorian public servants until the end of 2020. Accordingly, those services were affected by hiring freezes imposed by the Victorian Government and early retirement programs, which had increased Aruma’s reliance on casual staff. Mr Richardson expressed concern that casual staff are not legally obliged to disclose to Aruma the locations at which they have worked for other service providers or agencies.

210. The Australian Government’s submissions acknowledge that the casualisation of the disability workforce can pose risks. Even so, the Australian Government submits that:

> Employment status makes no difference to the risk of spreading COVID-19 in the absence of community transmission … If there is a higher level of community transmission, some of the features of a more casualised workforce may increase the risk of spreading COVID-19; however, these risks can be managed and reduced.

211. In our view, the assertion by the Australian Government that employment status is immaterial to the risk of transmission misses the point. It is not employment status as such that creates the risk, but an ever-changing support staff. If many different staff members come in contact with people with disability during a particular period, the risk of infection is increased and people’s level of fear is likely to increase.

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326 Transcript, Andrew Richardson, Public hearing 5, 20 August 2020, P-294 [20-24].
327 Exhibit 5.250, Statement of Andrew Richardson, 16 August 2020, at [109].
Access to PPE

212. Mr Ross Joyce of AFDO gave evidence that ‘service providers in the sector weren’t even recognised as able to access the PPE stockpile’ in the early days of the pandemic.\(^{330}\) Mr Richardson said that it was very difficult to get advice from government as to whether Aruma would be able to access PPE from the National Medical Stockpile.\(^{331}\) Both he and Ms Robbs thought that the difficulty arose because disability support staff were not regarded by government as an ‘essential service’ and were therefore not accorded priority for PPE.\(^{332}\)

213. Professor Kavanagh said in her statement of 12 August 2020 that ‘we are only seeing the distribution of PPE in the past month or so. Even so, getting that to everyone has been difficult.’\(^{333}\)

214. The Australian Government accepts that the disability workforce did not initially receive priority access to PPE from the National Medical Stockpile but attributes this to global shortages of PPE.\(^{334}\) The Australian Government’s submissions state that:

by early April, PPE was made available from the [National Medical Stockpile] to support services to people with disability in accordance with agreed protocols based on health needs, vulnerability and exposure to COVID-19.\(^{335}\)

\(^{330}\) Transcript, Ross Joyce, Public hearing 5, 18 August 2020, P-58 [10-13].

\(^{331}\) Transcript, Andrew Richardson, Public hearing 5, 20 August 2020, P-286 [10-15].

\(^{332}\) Transcript, Claire Robbs, Public hearing 5, 20 August 2020, P-287 [20]; Transcript, Andrew Richardson, Public hearing 5, 20 August 2020, P-286 [35-40].

\(^{333}\) Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [143].

\(^{334}\) Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [182].

\(^{335}\) Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [182].
Access to testing

215. Professor Kavanagh said in her statement that:

the disability workforce was not clearly defined as essential, and it was unclear whether the sector was included as a priority group for testing along with health and aged care sectors.  

216. The Forgotten workforce survey of disability support workers conducted by the Disability and Health Unit of the University of Melbourne found that when workers went for testing earlier in the pandemic, they were not treated by the health staff as a priority, even though the health care and aged care workforce had been identified as priority groups for testing at that stage. 

217. The Australian Government’s submissions indicate that testing arrangements are the responsibility of state and territory governments. The Australian Government also states that it has ‘facilitated priority access from mid-August 2020 to COVID-19 testing for all Victorian disability support workers’. 

Paid pandemic leave

218. A number of witnesses expressed the view that disability support workers should have access to paid pandemic leave. Professor Kavanagh, for example said that:

The potential for insecure, lowly paid workers to be forced into making impossible choices between losing income or attending work when sick, was pointed out by us and many other academics, unions and workers from the start.

219. The Australian Government’s submissions provided the following information:

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336 Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [144].
337 Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [145].
340 Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [142].
Following the outbreak in Victoria, on 3 August 2020 the Australian Government announced the Pandemic Leave Disaster Payment (Disaster Payment) whereby any eligible disability worker who is directed to self-isolate or quarantine receives $1,500 whilst undergoing mandatory self-isolation or quarantine. As at 16 September 2020, Western Australia, Victoria and Tasmania have accepted the Australian Government’s offer to fund the Disaster Payment program.\textsuperscript{341} [Emphasis in original]

220. Professor Kavanagh described the Disaster Payment as a welcome initiative, but one that came too late.\textsuperscript{342} We agree.

\textbf{Infection control training}

221. On 16 March 2020, the Department of Health published online material providing infection prevention and control training for care workers across the health, aged care, disability and other sectors.\textsuperscript{343} Mr Cotterell said in his evidence that there had been no evaluation of the effectiveness of the online training program since its release.\textsuperscript{344}

222. According to Professor Kavanagh, the \emph{Forgotten workforce} survey revealed that as of June 2020:

about a quarter of people … had not even done an online infection control training module in the disability support workforce, and of those that had, … nearly half of them actually wanted more training.\textsuperscript{345}

223. Professor Kavanagh said that she did not consider that the disability support workforce had been ‘properly prepared’.\textsuperscript{346} She thought that the \emph{Forgotten workforce} survey findings ‘pointed out the fact that we didn’t have a confident workforce’.\textsuperscript{347}

\textsuperscript{341} Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [184].
\textsuperscript{342} Exhibit 5.30, Statement of Professor Anne Kavanagh, 12 August 2020, at [141].
\textsuperscript{343} Exhibit 5.42, Statement of Simon Brook Cotterell, 10 August 2020, at [14].
\textsuperscript{344} Transcript, Simon Cotterell, Public hearing 5, 21 August 2020, P-326 [10-15].
\textsuperscript{345} Transcript, Professor Anne Kavanagh, Public hearing 5, 20 August 2020, P-216 [35-45].
\textsuperscript{346} Transcript, Professor Anne Kavanagh, Public hearing 5, 20 August 2020, P-216 [35-45].
\textsuperscript{347} Transcript, Professor Anne Kavanagh, Public hearing 5, 20 August 2020, P-216 [35-45].
224. Counsel Assisting’s submissions proposed that the Department of Health should evaluate the effectiveness of the online training program released on 16 March 2020 and in doing so take into account the Forgotten workforce report. The Australian Government accepts the proposed recommendation\(^{348}\) and records that it has implemented five of the recommendations in the report.\(^{349}\)

**Findings and recommendations**

225. We make the following findings:

225.1 People with disability in disability accommodation settings, especially those with co-morbidities, were exposed to a greater risk of infection than other members of the community (including other people with disability) during the early stages of the pandemic. The heightened risk was due to the extent to which service providers relied on casual disability support staff.

225.2 During the early stages of the COVID-19 pandemic the Australian Government did not provide disability support workers priority access to personal protective equipment, thereby exposing both the workers and the people with disability whom they supported to an increased risk of infection.

\(^{348}\) Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [188].

\(^{349}\) Submission of the Australian Government, Public hearing 5, 18 September 2020, SUBM.0003.0010.0014 at [189].
**Recommendation 17:**

The Australian Government in coordination with the states and territories should take all practicable steps to ensure that in the event of a resurgence of COVID-19, disability support workers have priority access to:

- PPE and
- testing for COVID-19.

**Recommendation 18:**

The Australian Government in coordination with the states and territories should set in place arrangements to ensure that in the event of a future pandemic, disability support workers have priority access to:

- PPE and
- appropriate testing procedures.

**Recommendation 19:**

The Australian Government Department of Health should evaluate the effectiveness of the online training program released on 16 March 2020, taking into account the report *Disability Support Workers: The forgotten workforce in COVID-19.*
Health care rationing

226. A number of witnesses expressed their fear and concern about health care rationing. Health care rationing refers to determining priorities when the demand for health services exceeds the supply of services. The most notable example is allocating intensive care beds when patient numbers exceed beds available.\(^{350}\)

Concerns about health care rationing decision-making

227. Dr Dinesh Palipana gave evidence that some people with disability feared that it might be thought necessary to introduce health care rationing and if rationing occurred, they feared that people with disability would be seriously disadvantaged.\(^{351}\) This would occur, for example, if people with disability were triaged out of health care during the pandemic in favour of treating people without disability. Dr Palipana pointed out that health care rationing has occurred in some overseas places such as Italy and Texas.\(^{352}\)

228. FPDN, in partnership with researchers,\(^{353}\) developed a policy document entitled *Ethical Decision-Making for First Peoples Living with Disability*.\(^{354}\) This document outlines principles and recommendations regarding care for First Peoples living with disability. It also provides specific guidelines for determining priorities among and treatment of patients presenting to Intensive Care Units.

229. Mr Griffis expressed concern that ‘people who are disadvantaged would often score lower on these types of point ranking systems, and

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\(^{350}\) Exhibit 5.13, Statement of Dr Dinesh Palipana, 4 August 2020, at [18].
\(^{351}\) Exhibit 5.13, Statement of Dr Dinesh Palipana, 4 August 2020, at [18]; Transcript, Dr Dinesh Palipana OAM, Public hearing 5, 20 August 2020, P-236 [22-26].
\(^{352}\) Transcript, Dr Dinesh Palipana OAM, Public hearing 5, 20 August 2020, P-236.
\(^{353}\) Professor Cameron Stewart (Sydney Health Law, University of Sydney) and Professor Jackie Leach Scully (Disability Innovation Institute at the University of New South Wales).
\(^{354}\) Exhibit 5.34.3, FPD.9999.0001.0027.
it is those same people who miss out on receiving appropriate medical attention and care’. He said that:

it was a fear of FPDN that in Australia it would be First Peoples with disability, who are already experiencing higher levels of disadvantage and are extremely vulnerable to COVID-19, who would be triaged out of the health system or be provided with inadequate support.

Mr Griffis observed that:

it’s often the case that in particular regional-based hospitals … there is a reputation often of Aboriginal people experiencing racial discrimination.

230. The document was shared at a Department of Health roundtable, and Mr Griffis noted that it had been ‘well received’.

231. Ms Devandas gave evidence that the COVID-19 pandemic is revealing and deepening pre-existing inequalities and barriers experienced by people with disability and exposing the extent of their exclusion. She expressed the view that a strong human rights-based framework is still lacking in relation to health issues experienced by people with disability. As a consequence, the health of people with disability may be seriously affected due to serious disruptions to their support services and discrimination when they attempt to access emergency health services.

232. On 14 April 2020, a number of representative and advocacy organisations published a statement of concern entitled COVID-19:
Human rights, disability and ethical decision-making. The statement was drafted in response to a concern that:

any increasing demand on critical health treatment and intensive medical care will require decisions to be made about life-saving treatment that could seriously undermine the rights of people with disability.

233. Ms Kayess, who was a co-author of the Statement of Concern, spoke about health care rationing proposals from Canada and England, which ‘highlighted the ways that decisions were going to be made about critical care triage’. She said that these decisions ‘were being made on blatant[ly] arbitrary diagnostic status with no clinical reference whatsoever’. This meant that there was ‘no recognition of a person’s rights to equality in the standard of health care’ and based primarily on their diagnostic status, people with disability ‘would not receive critical care’.

234. Dr Palipana observed that the United Kingdom’s National Institute for Health and Care Excellence’s COVID-19 rapid guideline: Critical care in adults, calls on decision-makers ‘to consider how frail a person is and if they are considered to be too frail, based on any of these disabilities, the guidelines suggest that you defer critical care for these patients’. He compared these guidelines with the Australian and New Zealand Intensive Care Society (ANZICS) Guiding principles for complex decision making during Pandemic COVID-19. ANZICS calls for ‘respect among all patients’ and asks ‘practitioners to ignore unnecessary considerations such as race, gender, sexual orientation and disability’. Dr Palipana stressed that while these guidelines

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365 Transcript, Rosemary Kayess, Public hearing 5, 18 August 2020, P-38 [8-9].
366 Transcript, Rosemary Kayess, Public hearing 5, 18 August 2020, P-38 [9-10].
367 Transcript, Rosemary Kayess, Public hearing 5, 18 August 2020, P-38 [10-13].
368 Transcript, Dr Dinesh Palipana OAM, Public hearing 5, 20 August 2020, P-236 [34-37].
369 Transcript, Dr Dinesh Palipana OAM, Public hearing 5, 20 August 2020, P-237 [1-7].
build in protections for people with disability, intensive care medical practitioners ‘still need to be vigilant’ to ensure that their clinical decision making is not affected by conscious or unconscious bias against people with disability.\[370\]

235. Dr Palipana also highlighted the importance of ensuring that clinical decision makers are aware of the ANZICS guidelines:

[The] most important thing is to look at this from a societal perspective. I think we've seen that the pandemic can be controlled and at least suppressed if we all gather round and do the right thing … So I think the single most important recommendation is to get the messaging out, that by doing the right thing we’re protecting the most vulnerable people in our society.\[371\]

236. Dr Coatsworth was asked whether the ANZICS guidelines reflect the Department of Health’s policy in terms of the allocation of critical care where the demand exceeds capacity.\[372\] He replied that currently no nationally-endorsed guidelines expressly adopt the ANZICS principles.\[373\] However, he stated that the Australian Government concurs with ANZICS’ view that disability is absolutely irrelevant to the allocation of ventilators where demand exceeds capacity.\[374\]

237. Dr Coatsworth was also asked the following question:

When a hospital or its senior intensive care specialists prioritise the provision of limited life-saving resources like ventilators, would you agree the following steps should be taken to assist in ensuring the rights of people with disability are protected? First, clearly articulating within any relevant policy including the one derived from ANZICS’ general principles that all decisions must, first, be clinically-based; second, include a medical assessment of the individual patient; thirdly, not be based on assumptions about the quality of a person's life after treatment because of their disability.

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\[370\] Transcript, Dr Dinesh Palipana OAM, Public hearing 5, 20 August 2020, P-237.
\[371\] Transcript, Dr Dinesh Palipana OAM, Public hearing 5, 20 August 2020, P-241 [27-43].
\[372\] Transcript, Dr Nick Coatsworth, Public hearing 5, 21 August 2020, P-368 [10-20].
\[373\] Transcript, Dr Nick Coatsworth, Public hearing 5, 21 August 2020, P-368 [10-25].
\[374\] Transcript, Dr Nick Coatsworth, Public hearing 5, 21 August 2020, P-368 [10-25].
Then, providing for an independent review of any decision not to allocate life-saving resources to a person with disability or otherwise. And finally, providing patients with access to an independent health advocate. Would you agree with that approach?  

238. Dr Coatsworth responded ‘In broad terms, yes, I would, Counsel.’

**Findings and recommendations**

239. We make the following findings:

239.1 Fortunately Australia has not had to confront a situation where COVID-19 has led to the demand for intensive care unit beds outstripping the number of beds available. Nor is there any evidence that in such a situation the Australian Government Department of Health or any other health authority in Australia would have rationed intensive care unit beds in a manner that discriminated against or unfairly prejudiced people with disability.

239.2 Nonetheless during the pandemic many people with disability have held genuine fears that health care rationing would be introduced and that if it was, people would be denied access to intensive care unit beds and other essential health services solely by the reason of their disability.

239.3 Although the Australian and New Zealand Intensive Care Society developed guidelines that guard against health care rationing during the pandemic on the basis of disability, the Australian Government Department of Health has published no such guidelines. Had it done so, the published guidelines may have reassured those people with disability who feared the introduction of health care rationing.

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375 Transcript, Dr Nick Coatsworth, Public hearing 5, 21 August 2020, P-368 [25-38].
376 Transcript, Dr Nick Coatsworth, Public hearing 5, 21 August 2020, P-368 [38-40].
Recommendation 20:

The Australian Government Department of Health should publish guidelines making it clear that access to health services during the pandemic will never be rationed by denying people with disability access to such services by reason of their disability.

Recommendation 21:

These guidelines should be drafted in consultation with the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability and should explicitly address access to intensive care units and to a COVID-19 vaccine, if and when one becomes available.

Recommendation 22:

The Australian Government Department of Health should recommend to relevant state and territory departments and agencies that they publish similar guidelines. Such statement could be formulated, for example, by the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability and endorsed by the Australian Government Department of Health. It should explicitly address access to intensive care units as well as access to a COVID-19 vaccine, if and when one becomes available.

Concluding comments

240. This report records the experiences of people with disability during the COVID-19 pandemic and lays bare uncomfortable truths about systemic inequality in Australia. Discrimination, isolation and exclusion, together with an increased risk of violence, abuse, neglect and exploitation, arise when the Australian Government fails to give appropriate consideration to all members of our community in its responses to a grave public emergency.
241. The report exposes the neglect experienced by many people with disability, especially those with high support needs, during the early (crucial) stages of the COVID-19 pandemic. It is true that the pandemic, an event unprecedented in modern times, was bound to have a significant effect on all Australians regardless of the responses by the Australian Government. But the impact of the pandemic on many people with disability, especially those with high support needs, would have been significantly ameliorated if the Australian Government had complied fully with the letter and spirit of its obligations under the CRPD from the very outset of the pandemic. Had the Australian Government done so it is very likely that:

- the levels of fear and anxiety experienced by many people with disability would have been lessened
- fewer people with high support needs would have suddenly lost essential supports or been unable to obtain essential supplies of food and medication
- people with disability and disability support workers would have had access to PPE and testing for COVID-19 earlier than occurred
- many people with disability, especially those living in disability accommodation settings, would have experienced less severe impacts on their physical and mental health.

242. We intend this report to expose the failure of the Australian Government during the early stages of the COVID-19 pandemic to adequately protect the human rights of people with disability. We intend the recommendations to provide the pathway to prevent a recurrence of the failure in the event of a resurgence of COVID-19 or the advent of another major national emergency. In those ways we intend the report to address the systemic inequality experienced by people with disability in Australia.
243. Since the report focuses on the response of the Australian Government to the pandemic, it deals only with one aspect of the systemic inequality and exposure to violence, abuse, neglect and exploitation experienced by people with disability. The Royal Commission will continue to investigate matters within the terms of reference, including matters related to the COVID-19 pandemic, that have not been fully addressed in this report. We intend to examine the responses of various levels of government as Australia continues to respond to the public health emergency. We also intend to review early in 2021 the Australian Government’s response to the recommendations in this report.

244. We express thanks and deep appreciation to all the people with disability, families and advocates who shared their experiences with the Royal Commission in submissions, in responses to the issues paper, in evidence and in other forms of engagement. Public hearing 5 could not have taken place, nor could this report have been prepared without their contributions.

245. We also thank the service providers, Australian Government agencies and experts who provided information and participated in the public hearing. The criticisms in the report of the Australian Government’s responses to the COVID-19 pandemic are not intended to reflect on the good faith or the intentions of the officials responsible for fashioning responses to the pandemic. They faced a difficult task.

246. We encourage all people with disability, their families and supporters to continue to share their experiences, ideas and hopes for change with the Royal Commission.
## Appendix A: Acronyms and abbreviations

List of acronyms and abbreviations used in this report.

<table>
<thead>
<tr>
<th>Acronym/Abbreviation</th>
<th>Expansion</th>
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<tbody>
<tr>
<td>Advisory Committee</td>
<td>Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability</td>
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<tr>
<td>Advisory Group</td>
<td>Aboriginal and Torres Strait Islander Advisory Group on COVID-19</td>
</tr>
<tr>
<td>AFDO</td>
<td>Australian Federation of Disability Organisations</td>
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<td>AHPPC</td>
<td>Australian Health Protection Principal Committee</td>
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<tr>
<td>Ann-Marie Smith Report</td>
<td>Independent review of the adequacy of the regulation of supports and services provided to Ms Ann-Marie Smith, an NDIS participant, who died on 6 April 2020, Alan Robertson SC, Report to the Commissioner of the NDIS Quality and Safeguards Commission dated 31 August 2020</td>
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<tr>
<td>ANZICS</td>
<td>Australian and New Zealand Intensive Care Society</td>
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<tr>
<td>CDNA</td>
<td>Communicable Disease Network Australia</td>
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<tr>
<td>CMO</td>
<td>Chief Medical Officer</td>
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<tr>
<td>COAG</td>
<td>Council of Australian Governments</td>
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<tr>
<td>CRE-DH</td>
<td>Centre of Research Excellence in Disability and Health</td>
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<tr>
<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities</td>
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<tr>
<td>CYDA</td>
<td>Children and Young People with Disability Australia</td>
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<tr>
<td>DANA</td>
<td>Disability Advocacy Network Australia</td>
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<tr>
<td>FPDN</td>
<td>First Peoples Disability Network Australia</td>
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<tr>
<td>First Nations Operational Plan</td>
<td>Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19): Management Plan for Aboriginal and Torres Strait Islander populations; Operational Plan for Aboriginal and Torres Strait Islander populations</td>
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<tr>
<td>Management and Operational Plan</td>
<td>Management and Operational Plan for People with Disability</td>
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<tr>
<td>National Communicable Diseases Plan</td>
<td>Emergency Response Plan for Communicable Disease Incidents of National Significance</td>
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<tr>
<td>NDIA</td>
<td>National Disability Insurance Agency</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Name</td>
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<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
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<tr>
<td>NDIS Act</td>
<td>National Disability Insurance Act 2013 (Cth)</td>
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<tr>
<td>NDIS Commission</td>
<td>NDIS Quality and Safeguards Commission</td>
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<tr>
<td>NDIS Commissioner</td>
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<td>NNDSS</td>
<td>National Notifiable Diseases Surveillance System</td>
</tr>
<tr>
<td>PPE</td>
<td>Personal Protective Equipment</td>
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<tr>
<td>Residential Care Facilities Guidelines</td>
<td>CDNA national guidelines for the prevention, control and public health management of COVID-19 outbreaks in residential care facilities in Australia</td>
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<tr>
<td>Royal Commission</td>
<td>Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability</td>
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<td>WHO</td>
<td>World Health Organization</td>
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