

Submission: Commonwealth Government COVID-19 Response Inquiry

The contents of this document are OFFICIAL.

Introduction

The Independent Advisory Council (IAC) represents the participant voice in the National Disability Insurance Scheme (NDIS) and provides advice to the Board of the National Disability Insurance Agency (NDIA). The COVID-19 pandemic significantly affected people with disabilities. The impact of COVID-19 on the health and wellbeing of people with disabilities has, and continues, to be significant. There has been 439 COVID-19 associated deaths of NDIS participants from March 2020 to 1 August 2023.¹ COVID-19 is still spreading throughout the community with new variants. The response to the pandemic from government has affected, and continues to affect people with disabilities, in particular those who are NDIS participants.

The Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability (Royal Commission) held two public hearings on COVID-19.² The recommendations from public hearing 5 and public hearing 12 of the Royal Commission were supported by the Senate Select Committee on COVID-19 in 2022.

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The IAC supports those recommendations and suggests there is an audit to confirm what the government have actioned.

This submission adds further information for the Commonwealth Government COVID-19 Response Inquiry (Inquiry) to consider. The three areas of the terms of reference which this submission covers are governance, key health response measures, and responses for people with disabilities.

Governance

Response measures for people with disabilities are in the Royal Commission reports for public hearings 5 and 12 and cover issues related to governance. The IAC supports the recommendations in these reports and highlights recommendations that focus on:

- People with disabilities consulted and included in advisory groups on emergency responses from the start.
- Providing funding and support for disability representative and carer organisations and people with disability to participate in consultations about planning for the COVID-19 pandemic and any future national emergency.
- Identification of any gaps in current consultation processes used by agencies responsible for the health and wellbeing of people with disability during the COVID-19 pandemic or other national emergencies.
- First Nations people with disability representation in the consultations and advisory groups.

IAC members note that the Royal Commission talks of consultation and inclusion on advisory bodies. Co-design with people with disabilities should be undertaken wherever possible for planning of responses to emergencies.

Members of the IAC have noted that government responses worked well for NDIS participants when all government departments and levels of government worked together to action things using the National Cabinet, advisory groups, and taskforces. This means the focus was on the agency with the capacity and skills to respond. Time spent debating who should or shouldn't act according to the usual practice's pre-pandemic did not help.

The COVID-19 Taskforce represented disability from April 2020 with individual representation. However, it appeared that people with disabilities as a priority group that needed support and access to essentials, were not added until after actions or initiatives were announced. There was little transparency on how the prioritisation of

groups occurred, with a lack of understanding from the Department of Health and Aged Care on the risks and co-morbidities for people with disability.

The Department of Health and Aged Care, as well as state and territory governments' health systems, have obligations to provide equitable access to support for people with disabilities. The pandemic highlighted how mainstream services were not meeting those obligations, and in an emergency, they had not done the planning to ensure people with disabilities would get the support they needed.

The NDIS supports over 630,000 people with disabilities in Australia according to the most current 2023 NDIA quarterly report.³ Participants cross a range of ages, disability types, and family and living situations. Although just under half of NDIS participants are under 18 years, the range of disabilities of participants include many who have compromised or low immune systems, or there are co-occurring health conditions. 10% of NDIS participants are Aboriginal and Torres Strait Islander people{ NOTEREF _Ref153536426 \h * MERGEFORMAT } and several participants live with complex and high levels of support needs in group settings. Given these factors, the disability community expected that people with disability, and particularly those people with disabilities on the NDIS, were seen as a priority group.

The NDIA are supposed to be an agency with expertise in disability, including communication accessibility and inclusion. In the broader context of the pandemic, the NDIA was expected to step up and respond immediately, however IAC members noted there was a tendency to keep pushing issues to Department of Health and Aged Care in the time of crisis.

Interagency and across government cooperation did occur through the mechanisms of advisory groups, taskforces, and the National Cabinet. For people on the ground, it was unclear how decisions flowed down to local government level and included and involved grassroots organisations. It was local peer and support organisations who were often taking action to respond to the needs of people with disabilities. It was also unclear how what was working at a local level was being shared through those governance mechanisms.

IAC members noted that grassroots organisations and some state governments responded to the needs of people with disabilities that weren't health related but were due to the impact of the health response. For example, the Victorian Government set up a disability liaison officer role, which assisted many people with

³ National Disability Insurance Agency (2023) *NDIS Quarterly report to disability ministers 30 September 2023*, NDIS website, accessed 15 December 2023.

disabilities to navigate the impact of the pandemic. Another example is where a trusted disability leader made short videos talking about where to get trusted sources of information for people with intellectual disability living in group accommodation. What worked well with these initiatives should have been shared through those national governance mechanisms.

Key health response measures

Key health response measures are in the Royal Commission reports for public hearings 5 and 12. The IAC supports the recommendations in these reports and highlight recommendations about:

- The disability workforce having access to personal protective equipment (PPE) as a priority during pandemics.
- That people with disability are recognised as a priority group during a pandemic, particularly people living in group accommodation.
- Priority access to vaccines and boosters is given to NDIS participants and workers, particularly in group accommodation and support.
- Priority is given to making communication and information easy to understand and accessible.

The pandemic is not over and the health responses for people with disabilities need to remain in place including vaccination messaging, priority access to PPE and other essential services. IAC members note there is still COVID-19 in the community and IAC members have shared that many people with disabilities do not feel safe in public and so limit their activities. There is a high level of anxiety about the reduced status of COVID-19 and the risks it holds for people with disabilities who are further marginalised by the general community not understanding that risk.

IAC members noted that communication and messaging from the Department of Health and Aged Care was often lagging behind new data and information. This meant there were always delays for information tailored for people with disabilities. Engagement with the NDIA on co-design of communication resources to support health responses needed to occur earlier and should be occurring now. During the pandemic, people were often turning to social media and getting misleading information. The NDIA can build a network of communication channels that can be activated during a pandemic.

The lack of understanding from the Department of Health and Aged Care on the risks and co-morbidities for people with disability contributed to the delayed response that was specific to people with disability from health and other systems. According

to the Australian Institute of Health and Welfare data there are 2.8 million people with chronic health conditions who also identify as having a disability. For example, the 2018 data shows 21% of people with coronary heart disease under the age of 64 identify as also having a disability.⁴

IAC members are concerned that changes made in the pandemic such as the use of telehealth for many appointments, are being reduced. These services and continued connection with the NDIA and Department of Health and Aged Care need to stay to keep risks to a minimum and allow for quick responses where there are fresh waves of COVID-19.

Responses for people with disabilities

Response measures for people with disabilities are in the Royal Commission reports for public hearings 5 and 12. There is overlap with the recommendations related to governance. The IAC supports the recommendations in these reports and highlights recommendations about:

- NDIS providers needing to be better prepared in the future for emergencies including pandemics.
- The option for NDIA planning done remotely and plans being extended, with more flexibility of funding use to respond to crisis and emergency situations.
- People with disabilities consulted and included in advisory groups from the start.
- First Nations people with disability represented in consultations and advisory groups.

IAC members noted the need to include the terms ‘parents’ and ‘caregivers’ in emergency materials, as children rely on their parents to know what might be needed in emergencies. Registered providers of early childhood intervention services must demonstrate as part of NDIS auditing, that they are providing resources to families of young children. Children and young people with disabilities that affect their respiratory and immune systems are a group who are vulnerable to COVID-19 and this group must be included in designing and receiving responses that suit their needs.

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IAC members noted the Royal Commission reports do not specifically speak to people with disabilities and families from culturally and linguistically diverse (CALD) backgrounds having culturally appropriate information. These communities were more vulnerable during the pandemic due to misinformation spread in their communities. Successful initiatives involved trusted community leaders and initiatives such as vaccinations in the mosque, or local community centres etc.

Approximately 8.5% of NDIS participants identify as CALD. { NOTEREF _Ref153536426 \h * MERGEFORMAT } However, easy to access information also needs to be available for the workforce and according to the National Skills Commission 40% of the care and support workforce were born overseas, and mostly from non-English speaking countries.⁵

Workforce issues in the disability sector took a long time to be recognised as an issue. The disability workforce is more distributed than aged care and in a diverse range of roles. Information often focused on health and care workers, where disability support workers were not mentioned and wondered if they were included.

IAC members noted the need for the disability sector workforce to be recognised as an essential workforce. This then opens the possibility of solutions such as targeted visa campaigns, and support for the workforce. IAC members noted that international students are a pool for casual work used in metropolitan areas and the pandemic impacted this workforce.

Some people with disabilities would restrict the number of workers they had to lower the risk of exposure to COVID-19. This would often put increased pressure on family and informal supports who were not compensated. Short-term flexible responses to paying family members would have assisted.

The Royal Commission recommendations did not talk about the experience of people with disabilities who identify as Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, Asexual Plus (LGBTIQA+). It was noted that there may also be issues of access to safe and appropriate workers that should be considered in this context.

For people with disabilities the impact of the pandemic was exacerbated by reduced access to supports and services, and reduction in disability supports. National networks like the local area coordinators (LAC) didn't seem to be used by the NDIA or government mechanisms as a group that people with disabilities could use for accessing information and coordination of supports during the crisis period.

⁵ National Skills Commission (2021) *Care Workforce Labour Market Study*, National Skills Commission, Australian Government.

Ensuring priority access to essential services to NDIS participants such as supermarket deliveries, transport, and health services like testing and vaccines was vital and must be factored into future emergency response planning. Although people with disabilities affected by the pandemic is broader than NDIS participants, being a participant was eventually used to fast-track access to things like shopping delivery, PPE, and COVID-19 rapid antigen tests.

Grassroots local organisations and key individuals often stepped in to come up with solutions without funding, particularly in remote areas or where there were gaps in supports. Examples include:

- Peer support organisations developing information in Easy Read, Auslan and videos before Australian Government agencies.
- The development of short videos by trusted disability leaders for people in group homes with factual information on COVID-19.
- An individual providing information in sign language for some remote Queensland and Northern Territory First Nations communities.
- Provider and community groups pivoting from providing recreation activities to free delivery of shopping and essentials.

Emergency funding that can be targeted locally and quickly to identified organisations, would assist with this ability of grassroots organisations to fill gaps quickly in ways that are tailored to people with disabilities.

IAC members noted that in emergency situations support for decision making often reduces. This is a time where the needs and wishes of people who need support for decision making should be heard. There is a need for planned increased support for decision making as part of emergency planning.

IAC members noted that the disability community stepped up to work together. Service providers, advocacy, disability leaders and peer support groups worked with each other through informal networks and relationships to make sure people were supported.

The Royal Commission recommendations include recommendations to continue doing things which have benefited people with disability. This includes plan extensions and longer plans for NDIS participants, which is already in place. IAC members noted that the availability of telehealth was a game changer for many people with disabilities and must be maintained. The other main benefit has been the ability to work from home and remotely. The IAC is hopeful these changes will remain and continue to benefit all people in the community.

Conclusion

The IAC recommends the Inquiry read and support the recommendations from the Royal Commission reports for public hearings 5 and 12. It is not clear if all the recommendations have been fully implemented, and a review is timely.

The IAC also highlights the need for planning of emergency responses to be co-designed with people with disability at the macro and individual level. As a group, people with disability are not recognised as a priority cohort. This may be because of their diversity of needs and distribution through community. However, their risks are greater than those of the general population. COVID-19 is still active in the community and the risks need to be recognised and managed.

The long-term impact of COVID-19 on people with disabilities is yet to be seen. It is recommended by the IAC that this is monitored. The impact being measured should include the wellbeing of people with disabilities and the impact of being at risk, as well as the health impacts of getting COVID-19. Many people with disability feel that the risk to their health is not taken seriously by the community.

The IAC would be open to sharing further information and examples with the Inquiry.

References

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The Department of Health and Aged Care, as well as state and territory governments' health systems, have obligations to provide equitable access to support for people with disabilities. The pandemic highlighted how mainstream services were not meeting those obligations, and in an emergency, they had not done the planning to ensure people with disabilities would get the support they needed.

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