



COVID-19

White Paper

Advocacy for Inclusion

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This is a consultation draft which does not necessarily reflect the final views of AFI

White Paper on COVID-19

OUR KEY PRIORITIES

- The situation of people with disabilities is a seminal test of the effectiveness of our health system and community responses to shocks, emergencies and disasters. From Hurricane Katrina to COVID, people with disability are often the first to feel the effects of disasters yet the last to be assisted.
- In an era characterised by rolling crisis, shocks and disasters, levels of equity, inclusion and social progress may come to be measured by the outcomes experienced by those hit first, hit hardest yet often left behind.
- The circumstances of people with disabilities also test the effectiveness and responsiveness of the health system requiring the application of the social model in a medical context while highlighting critical gaps in health service, information, outreach, treatment, infrastructure and the application of ethical standards.
- We offer as a bedrock principle the idea that, in a human rights jurisdiction, the effectiveness of the response to COVID should be assessed by its impact on those most vulnerable to it and not by majority public opinion.
- We offer four priorities.
 - Preventing disease and death amongst people with disability
 - Providing help to people with disabilities diagnosed with COVID
 - Preserving rights, supports, access and inclusion during the crisis
 - Learning lessons and listening to people with disability

COVID as a disability issue

- The COVID-19 pandemic continues to impact all of us and especially Australians with disability. We have high daily death rates, large numbers of people in hospital and fewer protections and supports. The ACT has had among the highest rates of COVID in Australia. 'Endemic' COVID is being experienced as a treadmill of infections and reinfections including among the vaccinated. There is growing and troubling evidence about the health consequences of long COVID. Large numbers are sick and there is disruption to supply chains and service continuity. There are other disease outbreaks occurring in an immune compromised population. Although the winter wave is passing, COVID isn't over for people with disability, even though we want it to be.
- COVID-19 and its management is a disability rights issue, consequential to Articles 11 and 25 of CRPD, and since 2020 there have been troubling gaps and delays in the formation of responses, the delivery of assistance and the availability of vaccines. In 2022 as BA4 and BA5 surge many people with disabilities find themselves with a series of bad choices – forced to shield or risk interactions in a community which has largely dropped protections at the same time as the pandemic worsens.
- National Cabinet should acknowledge that the COVID-19 pandemic continues to threaten the lives, health, social interactions and enjoyment of social, civil and political rights of people with disability. There should be a program of work to address this involving disability ministers and health ministers.
- Governments need to be guided by precautionary public health principles and human rights principles, including CRPD Article 11, in managing the

- pandemic.
- AFI joins leaders in public health and across the disability community in questioning the current approach of ‘living with COVID’.
 - We question whether the current trajectory of relying on vaccine only strategies, removing protections and moving towards uncontrolled transmission of COVID is sustainable given:
 - the high mortality rate which falls on older people and people with disability;
 - the ongoing levels of illness, debility and disease across the community resulting in workforce shortages in industries essential for the supply of goods and services;
 - the prevalence of disability because of long COVID;
 - the emergence of opportunistic breakout infections; and
 - the disproportionate impact of policies which allow community transmission on the lives, health and freedoms of older people and people with disability.
 - There needs to be an honest conversation about the social, human rights, moral and economic implications of the current policy trajectory and the voices, rights and agency of disabled people need to be amplified and listened to. Relevant lessons need to be applied from other pandemics including HIV and AIDS including the agency of vulnerable populations.
 - We support the position of OzSage which aims for elimination of uncontrolled transmission with layered, whole of society protections addressing safe indoor air, respiratory protection and optimal vaccination – a vaccine-PLUS strategy
 - In the meantime, Governments have asked people with disability and immune compromised people to take personal responsibility for their own health care during the pandemic. This requires Governments to reciprocate with actions, policies and modes of delivery that enable people to minimise their risks.
 - There are urgent priorities for Governments to ensure that people with disabilities are supported, protected and treated with fairness and decency in pandemic circumstances. These are as follows

Priority 1: Preventing disease and death of people with disability.

- We support [OzSage recommendations](#) for co-design of prevention and control strategies, higher vaccination coverage targets for people with disability, vaccination of all disability workers, strategies to reduce transmission risk including safe indoor air and mask use, prioritisation of third doses for people with disability, better support for COVID-19 patients with disability, ensuring people with disability are not deprioritised in access to health care, and improved data quality and reporting.
- Prompt and timely **access to vaccines and successive booster shots** for people with disabilities including people outside of residential settings.
- Prompt, timely and available **access to anti-virals and other treatments** including for people outside of residential settings.
- **Mask mandates and other protections in disability service and residential settings need to be retained** until uncontrolled community transmission of COVID has ceased. Appropriate exemptions and job redesign strategies should support those unable to don masks and protective

equipment with disability

- **Rapid Antigen Tests should be freely available** to people with disability – with a high risk of complications. These should be offered to NDIS clients and to people with concession cards. The decision to make them available via libraries is welcomed. They should also be made available to people who cannot get to libraries.
- **Payments and support systems** should be geared to ensure low income and casualised people, who make up the bulk of the disability care and support workforce, are not forced back into work while sick. The pandemic leave payment should be retained and isolation requirements after infection should be retained with a margin of error and safety for disability and aged care workers (at least 7 days)
- There must be **COVID-safe health services, Inreach services** and a **COVID-19 Inclusion Guarantee** so that people who are shielding from the pandemic can take steps to minimise their risk and access essential health care, goods and services and supports needed to stay viable.

Priority 2. Helping people diagnosed with COVID

- The **ACT Disability Health Strategy** should prioritise the provision of accessibility and supports for people with disabilities needing treatment for COVID19
- **Home based and in-reach supports should be available** to people with disability and older people to keep people out of hospitals
- People with disability and older people should have **access to antivirals** (not just people in residential settings)
- Governments and acute care settings need to ensure **ethical and non discriminatory treatment of people with disability who contract COVID-19**. Health care must not be denied or limited based on impairment. Government Guidelines for ethical treatment as well as the Statement of Concern issued in April 2020 should be widely available, disseminated, included in training and closely observed.
- **Outreach to all NDIS clients:** Advice should jointly developed by ACT Health and the NDIA and be provided to all NDIS clients in the ACT on: what to do if they get COVID (including where to go for medical help, how to discuss antivirals) and, how to ensure continuity of supports and essential supplies
- **Long COVID should be recognised as a disability** and people with long COVID should have access to disability and income supports including the NDIS, supplementary aged care package support and the Disability Support Pension.

Priority 3: Preserving rights, supports, access and inclusion

- Responses must **centre disabled people in the pandemic**– supports should be developed and provided based on the reality of the pandemic as it is experienced and responded to by disabled people – not how governments would like people to respond as they urge the community to live with COVID.
- **Flexible disability supports** should be enabled to respond to respond to urgent circumstances including, where needed, flexible use of funding to maintain core supports, food security, health and community connection. This requires flexibility from the NDIA, integration with tier 2 supports and

- continued responses from emergency providers.
- Accessible **COVID-safe health services** should be available
 - The Federal Government should maintain **funded access to telehealth including longer consultations** within the Medicare Schedule
 - **Health inreach services** for people with disability at risk of serious complications from COVID who cannot safely go to a health setting but need face to face diagnosis or treatment
 - The **Access and Sensory clinic should be retained** to provide vaccinations and other care in a quiet, COVID-safe and accessible environment
 - **Reduce risk of transmission in places people with disabilities must go.** We should prioritise **COVID-safe medical, dental, psych and walk in services** where people shielding from COVID-19 can access face to face primary and preventative health care while managing their risk – these should have clean air, mandated mask wearing, social distancing protocols and mandated vaccination status requirements for patients and visitors. All health care settings should be safe but it may be that we need to designate some safe spaces in transition.
 - Governments should work with people with disability to develop a **COVID-19 Inclusion Guarantee** which describes the steps, rights, supports and safeguards available to people with disability at risk of complications from COVID19 in the COVID era while uncontrolled transmission continues without improved vaccines and treatments. This should include:
 - A **non contact service framework** for mandating the continued enjoyment of essential services, civil and political rights for people shielding from COVID including requirements for all government service contacts, consultations and service delivery to be mirrored, as far as possible in a non-contact way. We note that there is some good work underway with Access Canberra on services but in other areas this is uneven.
 - **No person with disability should be required to attend a face to face meeting** to: continue to receive disability supports, to maintain a social housing tenancy, to access income support; or to retain concessions, licences, access to utilities or undertake banking
 - **Rights to work and study from home for people with disability** should be mandated by law (industrial and anti discrimination). People should not be forced to choose between retaining their lives and bodily integrity and retaining an income or education attainment. No person with disability should be forced to return to an unsafe classroom, lecture hall, worksite or office against medical advice. Federal and ACT public sectors should be model COVID safe employers of people with disability.
 - The **additional costs of disability arising from COVID-19** – such as the need to rely on non-contact deliveries and avoid mass transit should be better understood and responded to through income support and the tax systems
 - Governments, employers and education providers should organise to make fair and **equitable contributions to the costs of online access**

to home based work and study as the provision and upkeep of this infrastructure shifts from colleges and workplaces to homes.

- There should be **funded supports and community development work** aimed at improving social and community connectedness amongst people forced to shield from the pandemic. This might include ongoing grants, fostering online support networks and other innovative work (like safe spaces and special access events).

Priority 4: Learning lessons and listening to people with disability

- **Centre disabled people in the long haul response:** Lessons must be learnt from COVID19 in conjunction with Disabled Peoples Organisations. Just as a successful Australian response to HIV AIDS centred the experiences of gay men in the health crisis so the response to COVID needs to attend to the wisdom and knowledge of those at risk including people with disabilities at risk of health complications.
- **Set aside funds to respond:** Contingency funds should be reserved by Governments, including the ACT Government to mitigate the effects of COVID on people with disability and other vulnerable Canberrans. This should include funding for public health measures, service continuity, social inclusion and information to people with disabilities impacted by COVID19.
- **Flexibility:** Governments – along with the National Disability Insurance Agency - need to do ongoing work to develop systems and protocols which allow them to alter Business as Usual operations to respond to the needs of people with disability in the pandemic

The evidence

- The official global death toll from COVID-19 reached 6.44 million as of August 2022, however estimates of the actual impact of COVID-19 are far higher.¹
 - For example, The Economist estimates that there have been 20.7 million excess deaths²
- Before the pandemic, an estimated 15% of the global population had a disability. COVID-19 is now adding to those ranks apace.
- Emerging studies indicate the disproportionate impact of COVID-19 on people with disabilities. For example,
 - In the UK, nearly 60% of the people who died from causes involving COVID-19 in 2020 had a disability.
 - People with disability in the UK were three times more likely to die from COVID-19, with greater disparities at younger ages.³ Mortality is higher still (three to five times) among adults with intellectual disability.

¹ The World Health Organization now estimates 15 million, based on excess mortality which includes deaths missed by national reporting systems. See e.g., Adam (2022) [‘The pandemic’s true death toll: millions more than official counts.’](#) *Nature* 601(7893), pp. 312-305.

² The Economist (2021) [‘The pandemic’s true death toll: Our daily estimate of excess deaths around the world.’](#) 2 November 2021; accessed 28 July 2022.

³ Office for National Statistics (2021) [‘Updated estimates of coronavirus \(COVID-19\) related deaths by disability status, England: 24 January to 20 November 2020.’](#) Accessed 28 July 2022.

- Children less than 16 years of age with intellectual disability have six to nine times higher rates of hospitalisation in the UK.⁴
- In the United States, case fatality rates were much higher for people with intellectual disabilities compared to non-disabled counterparts at younger ages such as <17 (1.6% vs. 0.01%), and 18 to 74 (4.5% vs. 2.7%).⁵
- In a Canadian province, hospitalisation and mortality rates for COVID-19 are higher for adults with intellectual disabilities than in the general population, especially among younger age groups. Individuals with Down syndrome died at a rate 6.6 times higher than those without intellectual disabilities.⁶
- In South Korea, the odds for death from COVID-19 infection were 6.5 times higher among people with disabilities as compared with their non-disabled counterparts.⁷
- There have been close to 10 million cases of COVID in Australia and 199,673 in the ACT
- There have been 13,156 deaths in Australia and 116 in the ACT
 - On the day of writing there were 134 deaths in Australia
- There are approximately 4.4 million Australians living with a disability. The NDIS currently supports more than half a million Australians. Aside from NDIS participants, many people with disabilities have had COVID in Australia and ACT.⁸
- There have been 23,778 cases reported amongst NDIS participants with 492 in the ACT. 83 NDIS participants have died and none are reported in the ACT.⁹
- There have been 3,762 deaths in residential aged care across Australia¹⁰
- Based on infections so far 400,000 people are likely to be left with disabilities due to COVID with over 100,000 people with a serious disability, and another 300,000 with activity limiting disabilities¹¹

⁴ Williamson, E.J., McDonald, H.I., Bhaskaran, K., Walker, A.J., Bacon, S., Davy, S., Schultze, A., Tomlinson, L., Bates, C., Ramsay, M. and Curtis, H.J., (2021). Risks of covid-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform. *bmj*, 374.

⁵ Turk, M.A., Landes, S.D., Formica, M.K. and Goss, K.D., (2020). Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disability and health journal*, 13(3), p.100942.

⁶ Lunskey, Y., Durbin, A., Balogh, R., Lin, E., Palma, L. and Plumptre, L., (2022). COVID-19 positivity rates, hospitalizations and mortality of adults with and without intellectual and developmental disabilities in Ontario, Canada. *Disability and health journal*, 15(1), p.101174.

⁷ Jeon, W.H., Oh, I.H., Seon, J.Y., Kim, J.N. and Park, S.Y., 2022. Exposure to COVID-19 infection and mortality rates among people with disabilities in South Korea. *International Journal of Health Policy and Management*. Early view 27 June 2022, p. 2.

⁸ The high PCR test positivity, and accessibility and reporting issues with Rapid Antigen Tests (RATs) mean that reported case numbers in Australia are likely to be significantly higher than official reports.

⁹ Note that the case data include confirmed cases only and does not take into consideration excess mortality. In addition, case numbers relate only to a subset of NDIS participants who use registered providers.

¹⁰ Australian Government (2022) '[Coronavirus \(COVID-19\) case numbers and statistics](#)'. Department of Health and Aged Care. Accessed 18 August 2022

¹¹ Andrew, A., Cutter, K., Lang, J., Li, H., Lyon, R., Wang, Z., and Xu, M. (2022). '[How COVID-19 has affected Mortality and Morbidity in 2020 & 2021.](#)' Actuaries Institute, Australia, p. 80.

- Health inequities worsen during epidemics.¹² People with disabilities are at higher risk of infection, serious illness and death from COVID-19 due to higher rates of co-existing health conditions.¹³
- People with disability face a ‘triple jeopardy’ of higher risk from death, reduced accessibility to health and social care services, and the additional impact of social barriers.¹⁴
- The COVID-19 pandemic has meant people with disabilities are worse off and more excluded.¹⁵
 - In Australia, people with disability were more likely to report worsening physical health.¹⁶
 - Adults with disability were less likely to participate in a range of social activities leading to increased isolation.¹⁷
- With governments abandoning lockdown measures, 13% of people classified as clinically vulnerable in the UK continue to shield.¹⁸ Anecdotal evidence suggests Australians with disabilities are taking matters into their own hands and protecting themselves.¹⁹
- The World Health Organization estimates 10 to 20 per cent of people infected with COVID will experience ongoing symptoms.²⁰ A new study suggests Long COVID affects 1 in 8 adults.²¹
- Emerging findings from the Doherty Institute indicate that Australian health systems need to prepare to care for thousands of patients with Long COVID.²²
 - For example, 5 per cent of people diagnosed during NSW’s ‘first wave’ were still experiencing symptoms three months later.²³ Older people,

¹² Quinn, S.C. and Kumar, S., (2014). Health inequalities and infectious disease epidemics: a challenge for global health security. *Biosecurity and bioterrorism: biodefense strategy, practice, and science*, 12(5), pp.263-273.

¹³ Kamalakannan, S., et al. (2021). Health risks and consequences of a COVID-19 infection for people with disabilities: Scoping review and descriptive thematic analysis. *International journal of environmental research and public health*, 18(8), p.4348.

¹⁴ Shakespeare, T., Ndagire, F. and Seketi, Q.E., (2021). Triple jeopardy: disabled people and the COVID-19 pandemic. *The Lancet*, 397(10282), pp.1331-1333.

¹⁵ Brennan et al., 2020. [Disability rights during the pandemic: A global report on findings of the COVID-19 Disability Rights Monitor](#). p. 11.

¹⁶ Australian Institute of Health and Welfare (2022) [People with disability in Australia 2022: In brief](#). Catalogue number DIS 81, AIHW, Australian Government, p. 29.

¹⁷ Australian Institute of Health and Welfare (2022) [People with disability in Australia 2022: In brief](#). p. 31.

¹⁸ The Conversation (2022) [‘Many people are still shielding from COVID – and our research suggests their mental health is getting worse.’](#) 7 July 2022; accessed 28 July 2022.

¹⁹ SBS News (2022) [‘As COVID is allowed to ‘let rip’, these Australians are locking themselves back down.’](#) 16 January 2022; accessed 28 July 2022.

ABC News (2022) [‘Life in pandemic purgatory.’](#) 7 February 2022; accessed 28 July 2022.

²⁰ World Health Organization (2021) [Coronavirus disease \(COVID-19\): Post COVID-19 condition](#). 16 December 2021; accessed 28 July 2022. The true prevalence [remains contested](#).

²¹ Ballering, A.V., van Zon, S.K., olde Hartman, T.C., Rosmalen, J.G. and Lifelines Corona Research Initiative (2022). Persistence of somatic symptoms after COVID-19 in the Netherlands: an observational cohort study. *The Lancet*, 400(10350), pp.452-461.

²² Angeles, M.R., Wannan Arachchige Dona, S., Nguyen, H.D., Le, L.K.D. and Hensher, M., (2022). Modelling the potential acute and post-acute burden of COVID-19 under the Australian border re-opening plan. *BMC public health*, 22(1), pp.1-13.

²³ Liu, B., Jayasundara, D., Pye, V., Dobbins, T., Dore, G.J., Matthews, G., Kaldor, J. and Spokes, P., (2021). Whole of population-based cohort study of recovery time from COVID-19 in New South Wales Australia. *The Lancet Regional Health-Western Pacific*, 12, p.100193.

women, and those with comorbidities were less likely to report recovery.

- Long COVID is the latest reminder that epidemics have profound and lasting effects. Emerging insights indicate that disability is likely to account for the lion's share of COVID-19's overall health burden.²⁴

What people tell us

"AFI is hearing from people with disability who are being denied face to face healthcare services such as psychology services but also don't feel safe connecting with treatment at home because of their circumstances i.e, a DFV circumstance where the abuse is occurring where the telehealth appointment would occur. We are also hearing from people who don't feel safe going to services in person due to COVID. Both of these circumstances requires a COVID safe space where people needing urgent face to face can be guaranteed to receive it during the pandemic " – AFI Individual Advocate

"Some of us haven't left our homes in nearly a year and are becoming more and more isolated as protections are removed. I have had to reduce homecare, cleaning and physiotherapy because of the risk of COVID and I haven't visited a shop, park, cinema, friends house, museum or other public place since August 2021" – Canberra person with disability

RIGHTS AND FRAMEWORKS

Action in this area occurs in the context of frameworks for rights protections and disability inclusion as well as improving wellbeing

CRPD – Article 11 – Situations of risk and humanitarian emergencies

"States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international 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."

Wellbeing indicators

The ACT's response to COVID19 and other disasters effects progress on several domains which impact the quality of life for Canberrans especially:

Being healthy and finding the right care

Canberrans have good physical and mental health and can access the services they need to lead healthier lives and manage illness. Individuals take steps to proactively maintain good health with the support of health-promoting environments.

Feeling safe and being safe

Canberrans are and feel safe and secure around their families, homes, community and on-line. Including: Community resilience to emergencies

Being connected with family, friends and community

Canberrans are connected and supported within our community and come together in areas such as sport, culture, spirituality, religion and the arts.

²⁴ Else, H., (2022). The pandemic's true health cost: how much of our lives has COVID stolen? *Nature*, 605(7910), pp.410-413.

Relevant sections of the ACT Parliamentary Agreement

Health: ACT Labor will always deliver high quality health care when and where Canberrans need it. To continue to strengthen Canberra's health system, the Government will:

2.2 Continue to provide accessible COVID-19 testing facilities across Canberra for as long as is needed

17.7 Continue to implement the Disability Justice Strategy Action Plan and develop and implement a Disability Health Strategy

Disability: The Government will strive to ensure Canberra continues to be an inclusive community where all people feel they belong, are valued and supported. As part of this effort, we will:

17.1 Continue delivering grants programs that support disability inclusion

Australia's Disability Strategy themes

Health and Wellbeing

Outcome: People with disability attain the highest possible health and wellbeing outcomes throughout their lives

Good health and wellbeing are critical determinants of a person's quality of life. This is especially the case for people with disability. In addition to the physical aspects of health and wellbeing, improving mental health outcomes for people with disability is also a key focus of the Strategy. It is also important to address the social, cultural and economic determinants of health and wellbeing.

Policy Priority 4:

Disaster preparedness, risk management plans and public emergency responses are inclusive of people with disability, and support their physical and mental health, and wellbeing

The needs of people with disability should be catered for in disaster risk management plans and public emergency responses in order to protect their mental and physical health and wellbeing.

Before, during and after emergencies, people with disability may require targeted and accessible information and communication. They may also require additional assistance to plan and prepare for an emergency, additional assistance and appropriate support in the event of evacuation or physical isolation, and support through the recovery process.

Organisations responsible for emergency management should also work with those responsible for urban planning and design to understand where people with disability are at greater risk of harm during disasters, and how these risks can be reduced.

Including people with disability in disaster preparedness and risk management discussions, and related policy development, and consulting them in the very early stages of responding to and recovering from emergencies, will ensure their needs are accounted for.

Backgrounder

Where are we now

At the time of writing (August 2022), 6,428,661 people across the world have died from COVID. Estimates which use excess deaths are much higher.

The coronavirus has become the fourth leading cause of death globally, after heart disease, stroke, and lung disease.

There are approximately 500 new COVID infections a day in the ACT, 129 people in hospital and 3-4 daily deaths. Hospitals report significant pressures, bed block and

surge events.

The death toll from COVID is rising around Australia due to a highly infectious BA4 and BA5 variant. Cases in the ACT rose to 1000-1500 per day in July 2022. The national death toll is estimated to reach 15,000 by the end of 2022. 116 people have died in the ACT at time of writing.

COVID is likely to be with us for many years. Mutations are continuing to find ways around vaccination.

COVID is not the only outbreak of infectious disease. These include MonkeyPox and Hepatitis while Polio has been detected in London and New York state wastewater for the first time in two decades.

It may be that we are in a period of multiple pandemics which change life for some time driven by overpopulation, climate change and encroachment on wildlife. The overlay of an increasingly unstable and deteriorating geopolitical context is making the pandemic harder to manage.

While Governments initially attempted to control the pandemic through mandated lock downs, social distancing measures and compulsory masking the emergence of vaccines as well as political imperatives have lead to a shift in approach.

Governments now appear resigned to COVID becoming endemic in the population and are hoping a combination of the vaccines, treatments and public education will prevent the acute health system being overloaded and the presence of death and disease beyond levels the public is prepared to tolerate.

Unfortunately, the vaccines while a vital tool in preventing serious illness for many people, do not provide immunity from COVID which can jump into vaccinated people. Vaccines have limited life and need to be boosted with subsequent shots. In addition, reinfection can occur as early as 28 days from a previous COVID-19 infection. A proportion of the population is resisting vaccines, masks and other measures within the context of global dis and misinformation.

As the virus continues to burn through the global population it is frequently mutating and producing variants which are more infectious and are able to work around vaccines.

After two years of (comparably) low COVID rates due to border policies and lockdowns, Australia is experiencing a surge of cases and a rising death rate, with 13,156 deaths since the start of the pandemic.

The combination of new vaccine resistant variants and declining protections and supports to the community means 2022 is a challenging period in the pandemic. Since the beginning of winter 2022, more than 2.5 million cases have been reported.

Pandemic is not the only disaster facing vulnerable populations – since 2019 a chain of bushfire, floods, hail and severe weather events has impacted Australia.

This is a period where disaster preparedness is core work. Pandemics, supply chain disruptions, conflict, cyberterrorism aimed at digital and infrastructure assets, energy shocks, recession and severe weather events are features of the coming era.

Disability in the pandemic

Since a global pandemic was declared in March 2020 there have been huge impacts for people with disability in Australia and around the world. These have included

- Illness and comorbidity
- Death
- Disruptions to caring arrangements and service continuity
- Social isolation and separation from communities, natural supports, social inclusion, sports, recreation and family
- Shifts of learning, employment and services to online platforms which have included people with disability for the first time

People with disabilities have made up a large proportion of the sick and the dead around the world.

A study in the Lancet found COVID-19 had caused at least 4.7 million deaths globally by Sept 23, 2021, including almost 136 000 in the UK and that this included 61,416 disabled people. According to the Study:

Evidence regarding the risk of COVID-19 mortality among disabled people is limited. One exception is a nationwide study in South Korea, which showed that people with moderate or severe disability were six times more likely than non-disabled people to die from COVID-19, and were at higher risk of SARS-CoV-2 infection and major adverse clinical outcomes.

Despite limited evidence, there is a strong rationale for an association between disability and COVID-19 mortality. First, disabled people are on average older than non-disabled people, and older people have an increased risk of COVID-19 mortality. Second, disabled people might be clinically vulnerable as they are more likely than non-disabled people to have known risk factors for severe COVID-19 (eg, obesity and diabetes), and health conditions underlying disability might confer increased risk (eg, Down syndrome or Parkinson's disease).

Third, disabled people might be at increased risk of SARS-CoV-2 infection as a result of contact with carers, residence in care homes, or scarcity of accessible information on protective measures.

Fourth, outcomes might be worse in disabled people than in non-disabled people if they experience poor quality of treatment or barriers to accessing care.

Last, disabled people are more likely than non-disabled people to experience poverty and deprivation, which are associated with increased risk of COVID-19-related death²⁵.

In Australia there have been 83 confirmed participant deaths since March 2020. This is likely to be an undercount due to an approach to counting COVID deaths which sees them ascribed to underlying conditions rather than COVID.

The COVID pandemic has crossed over with hearings of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and the Commissions Responses to the pandemic and interventions and this along with key advocacy pieces in the ACT and nationally provides a useful base for a headline chronology

In March 2020, the Royal Commission issued a [Statement of Concern](#) about the

²⁵ Bosworth, M.L., Ayoubkhani, D., Nafilyan, V., Foubert, J., Glickman, M., Davey, C. and Kuper, H., (2021). [Deaths involving COVID-19 by self-reported disability status during the first two waves of the COVID-19 pandemic in England: a retrospective, population-based cohort study](#). *The Lancet Public Health*, 6(11), pp.e817-e825.

impact of the emerging COVID-19 pandemic on people with disability. They asked Australian governments to take all necessary measures to ensure the safety, health and wellbeing of persons with disability during the pandemic, especially people living in disability residential settings and people with cognitive disability.

In April 2020 Disabled Peoples Organisations Australia issued its own [Statement of Concern on COVID-19: Human rights, disability and ethical decision-making](#). The Statement warned authorities against treatment protocols which would see people with disabilities denied access to treatment, especially ventilation in Intensive Care, based on impairment. It followed reports of triage practice in Italy and the UK which had seen people with disabilities de-prioritising for treatment as ICU's experienced surge events. The statement was made by respected leaders and bioethicists and was endorsed by dozens of peaks, civil society organisations and 1000 prominent individuals.

The Royal Commission held an urgent public hearing (PH 5) from 18 to 21 August 2020 on the 'Experiences of People with disability during the ongoing COVID-19 Pandemic.' The Commissioners' Report on this hearing was presented to the Governor-General on 26 November 2020 and subsequently tabled in Parliament.

The report made a series of findings about the impact of the pandemic on people with disability and also made 22 recommendations directed to the Australian Government.

On 2 April 2021, the Australian Government announced that it supported, either in whole or in principle, 21 of the 22 recommendations.

The Royal Commission held a further public hearing on 'The experiences of people with disability in the context of the Australia Government's approach to the COVID-19 vaccine rollout' on 17 May 2021. The Commissioners' Report on PH 12 was presented to the Governor-General on 27 October 2021 and subsequently tabled in Parliament.

The Report included findings that the vaccine rollout for people with disability had been 'seriously deficient' and that people living in disability residential care had been 'deprioritised' in the rollout without any public explanation. The Commissioners' Report for PH 12 made seven recommendations.

On 29 October 2021 the Australian Government announced that it accepted six of the seven recommendations.

Almost two years after issuing the statement, the Royal Commission has said it remains deeply concerned 'that people with disability are still not being appropriately prioritised during this phase of the pandemic in relation to health care, disability support and the vaccine/booster rollout'. It identified the following ten areas of particular concern:

1. Overall de-prioritisation of people with disability and lack of regard for their health and wellbeing, indicating a lack of systemic preparedness and service coordination.
2. Significant data gaps and reporting in relation to vaccination rates and the rates of infection and mortality of all people with disability. Concerns around language used by governments in the public reporting of deaths relating to COVID-19, with respect to the underlying health status of individuals.

3. Access to vaccinations and boosters for people with disability and disability support workers across the whole community and in all regions, and insufficient levels of immunisation when restrictions were eased and during the current wave.
4. Severe disruptions to disability services and essential supports due to furloughing of staff, fears around transmission and a lack of access to testing.
5. Access to essential health services and fears of health rationing as health care systems become inundated. Access to newly approved anti-viral medications.
6. Lack of equipment (rapid antigen tests, PCR tests, Personal Protective Equipment) and support and guidance for effective infection prevention and control. Lack of accessible testing tools and accessible public health information or interpreting services for some people with disability.
7. Concerns with managing COVID-19 in the home for people for disability.
8. Lack of adequate and meaningful consultation with the disability sector and people with disability to inform this phase of the pandemic response.
9. Fears and isolation for people with disability, needing to shield at home for extended periods, with anxieties about both potential infection from those providing critical support to meet basic needs, and, conversely, a lack of access to these critical services.
10. Reduced formal and informal oversight mechanisms in closed residential settings for people with disability, with an increase in the risk of violence, abuse, neglect and exploitation.

In January 2022 peak Australian Disability organisations wrote to National Cabinet calling for three key policy responses from Australia's federal, state and territory governments to protect the lives and health of people with disability. They called on the Cabinet to:

- Ensure continuity of support by disability support workers by requiring NDIS disability support service providers to develop and maintain COVID-19 emergency care plans that respond to the issue of staff shortages.
- Provide free and accessible access to personal protective equipment (PPE), especially N95 or P2 face masks, oximeters, as well as rapid antigen tests (RATs) on an ongoing basis for people with disability as well as their support workers and carers.
- Ensure priority access and processing of polymerase chain reaction (PCR) tests for people with disability as well as their support workers and carers.

In August 2022, a National Audit report confirmed the vaccine rollout failed to provide priority for at-risk groups, including aged and disability care, and First Nations people.

We want to hear from people with disability

This is a ‘white paper’ – it isn’t final but is being issued to prompt discussion by AFI

Have your say until 30 September 2022

Consultation questions:

- **What do you think of the paper? Do you agree with its priorities or do you identify others?**
- **What more can be done to protect people from COVID?**
- **If we are to ‘live with COVID’**
 - **what are the trade offs that the community reasonably should make to ensure that people who are vulnerable are treated with decency and are able to carry on?**
 - **Is there a ‘sweet spot’ that would allow people with disability to feel safe but more included?**
- **What more could be done to enable you to feel safe?**
- **What more could be done to reduce isolation and build connection while the pandemic continues?**
- **What disability or related support do you think you may need if diagnosed with COVID?**
- **Do you have other feedback?**

To provide feedback please email:
Craig@advocacyforinclusion.org

About Advocacy for Inclusion

Advocacy for Inclusion acknowledges the Ngunnawal people as the traditional owners of the Australian land on which we work.

Advocacy for Inclusion provides national systemic advocacy and independent individual, self and advocacy for people with disabilities in the Australian Capital Territory. We are a Disabled Peoples Organisation which means most of our board, members and staff are people with disabilities. We represent all people with disabilities and recognise diversity.

We act with and on behalf of individuals to act on their own behalf, to obtain a fair and just outcome.

Advocacy for Inclusion works within a human rights framework and acknowledges the *United Nations Convention on the Rights of Persons with Disabilities* and is signed onto the *ACT Human Rights Act 2004*.

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