

## Advocacy for Inclusion

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The Committee Secretary  
Inquiry into Long COVID and Repeated COVID Infections  
The House Standing Committee on Health, Aged Care and Sport

Via email - [Health.Reps@aph.gov.au](mailto:Health.Reps@aph.gov.au)

Dear Committee Secretary

Thank you for the opportunity to make a submission to the Inquiry into Long Covid. This is a timely and welcome inquiry. This submission addresses – to varying extents – Terms of Reference 1, 2, 4 and 5 with a focus on Long COVID as a cause of disability, a cause of dual disability and a consequential factor in relation to the disability and healthcare systems.

### About us:

Advocacy for Inclusion is a national systemic body representing people with disabilities in the ACT. We write systemic advocacy in the form of submissions, reports and position papers on issues affecting people with disability.

We provide expert policy advice on issues affecting people with disabilities that come through our individual advocacy clients and strong membership base in the ACT.

We are a Disabled Peoples Organisation meaning that a majority of our members, Board and staff have disabilities.

### Background:

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. The rapid emergence and spread of new variants are complicating the effectiveness of current vaccines. 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. Additional disease outbreaks are also occurring in an already immuno-compromised population.

COVID-19 and its management is a disability rights issue, consequential to Articles 11 and 25 of CRPD. Since 2020 there have been troubling gaps and delays in the formation, coordination, and communication of timely responses, the delivery of assistance and the availability of vaccines and, more recently, anti-viral medications.

It is critical that past issues and challenges are not repeated in the response to and management of Long COVID.

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.<sup>1</sup> Mortality is higher still (three to five times) among adults with intellectual disability.
- Children less than 16 years of age with intellectual disability have six to nine times higher rates of hospitalisation in the UK.<sup>2</sup>
- 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%).<sup>3</sup>
- 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.<sup>4</sup>
- 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.<sup>5</sup>

There have been over 10 million cases of COVID in Australia and over 200,000 cases in the ACT.

There have been 15,899 deaths in Australia and 128 in the ACT.

There are approximately 4.4 million Australians living with a disability. The NDIS currently supports more than half a million Australians.

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<sup>1</sup> Office for National Statistics (2021) [Updated estimates of coronavirus \(COVID-19\) related deaths by disability status, England: 24 January to 20 November 2020](https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020). Accessed 28 July 2022.

<sup>2</sup> 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.

<sup>3</sup> 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.

<sup>4</sup> Lunskey, Y., Durbin, A., Balogh, R., Lin, E., Palma, L. and Plumtre, 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.

<sup>5</sup> 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.

There have been 26,930 cases reported amongst NDIS participants with 535 in the ACT. 91 NDIS participants have died and none are reported in the ACT.<sup>6</sup>

Aside from NDIS participants, many people with disabilities have had COVID in Australia and ACT.<sup>7</sup>

There have been 4,114 deaths in residential aged care across Australia.<sup>8</sup>

Health inequities worsen during epidemics.<sup>9</sup> 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.<sup>10</sup>

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.<sup>11</sup> Arguably additional disability from Long COVID is an additional jeopardy.

People with Long COVID also join a list of other disabilities which are taking time to be recognised, understood and responded to and we know this is poor way of responding to disability. The experience with Aspergers, Chronic Fatigue and ME CFS has shown that delays in understanding, recognising and treating conditions have long downstream costs.

#### *Our policy work*

AFI have commenced a program of work, consultation, analysis and policy work centred on COVID and disability. While this is ACT work it has support of some national DPO leaders and AFI have been asked to present the work to the December meeting of the COVID-19 Disability Advisory Committee which reports to the Chief Medical Officer, and regularly informs the:

- Australian Health Protection Principal Committee (AHPPC), and the
- Communicable Diseases Network Australia (CDNA).

The body of work has consisted of:

- [The White Paper on COVID19 and people with disability](#) issued in August 2022

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<sup>6</sup> 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.

<sup>7</sup> 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.

<sup>8</sup> Australian Government (2022) '[Coronavirus \(COVID-19\) case numbers and statistics](#)'. Department of Health and Aged Care. Accessed 17 November 2022.

<sup>9</sup> 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.

<sup>10</sup> 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.

<sup>11</sup> 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.

- A Forum with national thought leaders working at the intersection of COVID and disability rights on 2 September 2022
- A [Shared Statement](#) on COVID19 from thought leaders issued on 29 September 2022

### Long COVID and disability

Long COVID represents a major and fundamental health challenge, threatening to become a mass disabling event on a scale equal to HIV, Polio and World War II.

Based on infections so far 400,000 Australians 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 disabilities.<sup>12</sup>

Little is known about the increased risk of contracting Long COVID if you are already have a disability. This is complicated by the failure to identify symptoms or recognise how symptoms present, for example, among people with intellectual disability.<sup>13</sup> Disability support systems are driven by definitions and checklists that allow non-medical workforces to assess and approve candidates for support services. But those with “invisible illness” rarely meet such criteria.

This requires a research agenda deciphering the multidimensional nature of Long COVID and its connection with pre-existing conditions, its identification, management, and treatment among people with disability, as well as its long-term social and political implications.

Recent research warns that people who have had COVID are at an increased risk of developing brain disorders, such as psychosis, seizures or epilepsy, brain fog, and dementia, throughout the two years post initial COVID infection.<sup>14</sup> In addition, researchers have discovered a connection between reinfection and Long COVID.<sup>15</sup> For people with disability our experience is that acquiring an additional disability can be the difference between independence and entry into acute care.

The World Health Organization estimates 10 to 20 per cent of people infected with COVID will experience ongoing symptoms.<sup>16</sup> A new study suggests Long COVID affects 1 in 8 adults.<sup>17</sup>

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<sup>12</sup> 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.

<sup>13</sup> Rawlings, G., and Beail, N. (2022). '[Long-COVID in people with intellectual disabilities: A call for research of a neglected area.](#)' *British Journal of Learning Disabilities* (early view).

<sup>14</sup> Taquet, M., et al. (2022). 'Neurological and psychiatric risk trajectories after SARS-CoV-2 infection: an analysis of 2-year retrospective cohort studies including 1284437 patients.' *The Lancet Psychiatry* 9(10): pp. 815-827.

<sup>15</sup> Al-Aly, Z., Bowe, B., and Xie, Y. (2022). '[Long COVID after breakthrough SARS-CoV-2 infection.](#)' *Nature Medicine* 28: 1461-1467.

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

<sup>17</sup> 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.

Emerging findings from the Doherty Institute indicate that Australian health systems need to prepare to care for thousands of patients with Long COVID.<sup>18</sup> For example, 5 per cent of people diagnosed during NSW's 'first wave' were still experiencing symptoms three months later.<sup>19</sup> Older people, women, and those with comorbidities were less likely to report recovery.

While Long COVID clinics are being set up, there are no government-funded clinics for this type of nervous system dysfunction and private waiting lists are now long.

### Issues

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 in the long-term management and support to people in 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 our [Shared Statement on COVID](#) thought leaders in the disability community warned of a 'cascade of consequences' at the specific intersection of disability and Long COVID:

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<sup>18</sup> 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.

<sup>19</sup> 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.

The priorities identified in the White Paper were highlighted on many occasions as being essential to prevent a cascade of negative societal consequences. These consequences included a “tidal wave” of people with Long COVID, which presents a “ticking time bomb” for both the mental health and health care systems. Participants warned of the potential of Long COVID to “break” Medicare and the NDIS, if people were not adequately supported to avoid, or recover from, COVID. It was also noted that the long-term disabling impacts of COVID could decimate workplaces and exacerbate the current labour crunch including in care and support settings.

### Priorities for people with disability and Long COVID

In the meantime, we also suggest priorities for Governments to ensure that people with long COVID are supported, assisted and provided with the disability supports they need while doing what we can to manage pressure on disability support systems. In the meantime, we also suggest priorities for Governments to ensure that people with long COVID are supported, assisted and provided with the disability supports they need while doing what we can to manage pressure on disability support systems.

These are as follows:

1. *Recognise Long COVID as a disability*

People with long COVID are people with a disability and this should be clearly recognised. This has human rights and practical dimensions. We know from experience that it is disabilities that are unrecognised, disputed/or untreated which end up costing the most in human and economic terms.

2. *Reduce long COVID*

Governments should recognise the extent, prevalence and consequences of uncontrolled COVID transmission as a mass disabling event in the population and take steps to reduce long COVID and to acknowledge the likely impact on acute care systems, disability care and the NDIS. Protecting people from COVID also protects them from LongCOVID.

3. *Support people with long COVID with disability supports*

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.

4. *Support people with Long COVID to recover and rehabilitate*

Governments should work with health and rehabilitation programs to offer rehabilitation assistance to people with long COVID along with peer support, advocacy and healthcare. We should learn lessons from other disabilities where we have had an emerging understanding of their prevalence, impact and treatment (such as autism) about the importance of responding early to obtain better quality of life for people effected and to reduce the downstream impacts on service systems including the health system.

Everything we know about disability, when it creates impairment, tells us denying LongCOVID is a disability for reasons of classification will not reduce costs. It will ensure that responses, treatments, rehabilitation and service planning is fragmented and delayed and that costs are larger and unplanned for in decades to come.

5. *Support people with long COVID to participate*

The increase in the number of people with disability due to Long COVID is another reason to accelerate and bolster responses to ensure that people with disability have access to employment, education, goods, services and social infrastructure that Australia's Disability Strategy (ADS) and human rights protections.

This is also another reason for all States and Territories to have comprehensive Disability Health Strategies under the ADS which address barriers, accessibility, workforce and cultural issues in preventative, primary and acute care systems.

In addition some of the measures which we have suggested to enable people with disability to shield and carry on during COVID – such as mandated rights to work and study from home through an Inclusion Guarantee – also have the benefit of allowing people with disabilities and long term health conditions to continue to participate.

6. *Fund work and research on Long COVID including dual disability*

A program of study and action, followed by investment, should be commenced to understand and better manage the consequences of Long COVID including amongst people with a pre-existing disability. We should identify some research priorities including:

- Prevalence and heightened risk factors
- Impact of early intervention
- Impact of disability supports
- Demand modelling for disability supports
- Role of advocacy and peer supports
- Discrimination, social model and Long COVID
- Equity of access (diagnosis, management and treatment)

7. *Maintain contingency for Long COVID*

We are in a COVID era for many years to come. Contingency funds should be reserved by Governments to mitigate the effects of Long COVID on people with disability and other vulnerable Canberrans. A focus on early intervention has proved to be critical in managing other disabilities – work should also be undertaken to identify and understand the role of early intervention with Long COVID and to ensure supports are available so people with the condition are treated with compassion, support and decency.

AFI are happy to provide further information or discuss this submission at a hearing. You can contact me on 0477 200 755 or our CEO Nicolas Lawler on 0439 431 814.

Regards

(Signed by email)

**Craig Wallace**  
Head of Policy  
18 November 2022