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**Inquiry into Long COVID and Repeated COVID Infections**

Submission by AFDO

**November 2022**

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About AFDO

Since 2003, the Australian Federation of Disability Organisations (AFDO), a Disabled Peoples Organisation (DPO) and Disability Representative Organisation (DRO), has been the recognised national peak organisation in the disability sector, along with its disability specific members, representing people with disability. AFDO’s mission is to champion the rights of people with disability in Australia and support them to participate fully in Australian life.

Our member organisations represent disability specific communities with a total reach of over 3.8 million Australians.

AFDO continues to provide a strong, trusted, independent voice for the disability sector on national policy, inquiries, submissions, systemic advocacy and advisory on government initiatives with the Federal and State/Territory governments.

We work to develop a community where people with disability can participate in all aspects of social, economic, political and cultural life. This includes genuine participation in mainstream community life, the development of respectful and valued relationships, social and economic participation, and the opportunity to contribute as valued citizens.

**Our vision**

That all people with disabilities must be involved equally in all aspects of social, economic, political and cultural life.

**Our mission**

Using the strength of our membership-based organisations to harness the collective power of uniting people with disability to change society into a community where everyone is equal.

**Our strategic objectives**

To represent the united voice of our members and people with disability in national initiatives and policy debate.

To enhance the profile, respect and reputation for AFDO through our members.

To build the capacity and sustainability of AFDO and our members.

To foster strong collaboration and engagement between our members and stakeholders.

To enhance AFDO's connection and influence in international disability initiatives, particularly in the Asia Pacific region, through policy, advocacy and engagement

Our members

 **Full members:**

* Arts Access Australia
* Autism Aspergers Advocacy Australia
* Blind Citizens Australia
* Brain Injury Australia
* Deaf Australia
* Deafblind Australia
* Deafness Forum of Australia
* Down Syndrome Australia
* Disability Advocacy Network Australia
* Disability Justice Australia
* Disability Resources Centre
* Enhanced Lifestyles
* Multiple Sclerosis Australia
* National Mental Health Consumer and Carer Forum (NMHCCF)
* People with Disability WA
* People with Disabilities ACT
* Polio Australia
* Physical Disability Australia
* Women with Disabilities Victoria
* Women with Disabilities ACT

**Associate members:**

* AED Legal Centre
* All Means All
* Amaze
* Aspergers Victoria
* Disability Advocacy and Complaints Service of South Australia (DACSSA)
* Disability Law Queensland
* Leadership Plus
* National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD)
* Star Victoria
* TASC National Limited
* YDAS – Youth Disability Advocacy Service



Acknowledgements

AFDO acknowledges Aboriginal and Torres Strait Islander people as the traditional custodians of the land on which we stand, recognising their continuing connection to land, waters, and community. From our head office in Melbourne, we pay our respects to the Bunurong Boon Wurrung and Wurundjeri Woi Wurrung peoples of the Eastern Kulin Nation and to their Elders past, present, and emerging. We also pay our respects to the traditional owners of all lands on which we operate or meet around the country.

AFDO acknowledges people with disability, particularly those individuals that have experienced or are continuing to experience violence, abuse, neglect, and exploitation. We also acknowledge their families, supporters, and representative organisations and express our thanks for the continuing work we all do in their support.

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Introduction

As a national peak organisation, AFDO and its members represent disability specific communities with a total reach of over 3.8 million Australians. AFDO is dedicated to undertaking systemic advocacy across a range of disability types, with the goal of enabling all people with disability to be involved equally in all aspects of social, economic, political, and cultural life.

AFDO welcomes the opportunity to provide comment on the *Inquiry into Long COVID and Repeated COVID Infections* (the Inquiry) and thanks the Standing Committee on Health, Aged Care and Sport (the Committee) for their consideration in allowing extra time for the completion of this submission.

In this submission, AFDO will approach the issue of Long COVID and repeated COVID infections from a disability-centred perspective, with the understanding that Long COVID is a chronic illness that constitutes a disability under the UNCRPD definition.[[1]](#footnote-2) AFDO understands that the findings of this Parliamentary Inquiry will inform the national response, and so this submission will raise a number of issues that ought to be taken into account. In line with the Committee’s request, AFDO has endeavoured to keep this submission as concise as possible.

This submission will largely be responding to the following two points from the Terms of Reference:

1. The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID infections, their families, and the broader community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background; and
2. Best practice responses regarding the prevention, diagnosis, and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally.

Defining Disability and Long COVID

**Defining Disability**
Under the United Nations’ *Convention on the Rights of Persons with Disabilities* (CRPD), Article 1, persons with disability are defined as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”[[2]](#footnote-3)

In the Preamble, the CRPD further states:

*(e) Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others;* and *(h) Recognizing also that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person.[[3]](#footnote-4)*

The Australian Bureau of Statistics’ (ABS) 2018 Survey of Disability, Ageing and Carers (SDAC) considers a person to have a disability if they have “at least one of a list of limitations, restrictions or impairments, which has lasted, or is likely to last, for at least 6 months and restricts everyday activities. The limitations are grouped into 10 activities associated with daily living – self-care, mobility, communication, cognitive or emotional tasks, health care, reading or writing tasks, transport, household chores, property maintenance, and meal preparation”, in addition to schooling and employment.[[4]](#footnote-5)

**Defining Long COVID**
Multiple definitions have been proposed and are currently used to define Long COVID, also referred to as Post COVID-19 condition or Post-Acute COVID-19 Syndrome (PACS). The World Health Organisation (WHO) defines Long COVID as:

*… occur[ring] in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.[[5]](#footnote-6)*

In the USA, Long COVID is considered to occur when symptoms extend beyond four weeks after the initial infection, whereas in the UK, this distinction is made at 12 weeks. Research studies into Long COVID frequently employ the four-week definition.

Although the WHO’s definition of Long COVID would seem to align with the CRPD’s definition of disability, it is not considered so in Australia, meaning affected individuals are unable to access disability supports such as the National Disability Insurance Scheme (NDIS) or Disability Support Pension (DSP).

Prevalence of Long COVID in Australia

**Recent statistics**Although Australian research into Long COVID is still in its infancy compared to what has been undertaken internationally, the evidence that has emerged so far is extremely troubling. A study conducted by Australian National University (ANU) and published earlier this month indicated that approximately one in three adults who had contracted the virus had symptoms that lasted for longer than four weeks, a common indicator of Long COVID.[[6]](#footnote-7) This equates to slightly over 14% of the adult population of Australia.[[7]](#footnote-8) Furthermore, nearly 5% of Australian adults have had COVID-19 symptoms lasting three months or more.[[8]](#footnote-9)

In another study conducted by The Melbourne Institute, researchers found that 15.5% of those who had tested positive, equating to 1.2 million Australians, reported symptoms lasting for longer than one month, with a further 6% reporting symptoms lasting for three months or longer.[[9]](#footnote-10) The study also found that Long COVID was associated with worse mental health, and that Long COVID sufferers were more likely to report severe symptoms than those with a shorter illness. The most commonly reported symptoms included fatigue, shortness of breath, and “brain fog”.[[10]](#footnote-11)

An earlier study conducted by the University of New South Wales (UNSW) and NSW Health in 2021 during NSW’s ‘first wave’ similarly found that 5% of people diagnosed with COVID-19 were still experiencing symptoms three months later.[[11]](#footnote-12) With approximately eight million Australians estimated to have contracted COVID-19 so far, this could equate to 400,000 Australians experiencing Long COVID.[[12]](#footnote-13)

Though more data is required to gain a clearer picture of the situation, this preliminary research demonstrates the prevalence of Long COVID in the community and its potential to greatly increase the burden of disability.

Matters of Significant Concern

Having established an understanding of Long COVID as a disability and its potential to greatly increase the burden of disability in Australia, there are a number of key issues that AFDO would bring to the Committee’s attention.

**Numbers may be higher than current Australian research indicates**

* Presently, there is no official data on the number of people with Long COVID in Australia. New modelling from Deakin and the University of Tasmania estimates that up to 500,000 people could be experiencing Long COVID by the beginning of December, with more than one fifth of those suffering “significant impacts”.[[13]](#footnote-14)
* Comparisons with international data suggest that current estimates may be too low. A recent report by the CDC in the US found that approximately 20% of people who had COVID-19 later experienced symptoms that could be attributed to Long COVID.[[14]](#footnote-15) Dr Al-Aly, a clinical epidemiologist and one of the US’ leading Long COVID researchers, suggested that this statistic could likely also apply to Australia, meaning more than one million Australians could be affected.[[15]](#footnote-16)

**Vaccination appears to provide minimal protection against Long COVID**

* A US study of more than 13 million people – the largest cohort studied to date – suggests that vaccination provides only minimal protection against Long COVID, reducing the risk by a modest 15%.[[16]](#footnote-17) This is in contrast to earlier, smaller studies that reported much higher protection rates.
* The limited efficacy of vaccination in reducing Long COVID has been echoed in statements by Dr Steven Faux, Co-Director of the Long COVID Clinic at St Vincent's Hospital in Sydney, who stated that the majority of their patients contracted the Omicron strain and were vaccinated. This mirrors international research that showed those who were triple vaccinated and infected with the Omicron strain had a Long COVID rate of 5%.[[17]](#footnote-18)
* Similarly, data analysis from almost 300 respondents in the ‘Australia Long COVID Community Facebook Group’ revealed that the vast majority were double vaccinated and infected with the Omicron strain before acquiring Long COVID.[[18]](#footnote-19)

**Downplaying of Long COVID by CMO and implications for public health response**

* Despite the research findings described above, in a press conference following the cessation of the mandatory national isolation requirements on 14 October 2022, Chief Medical Officer (CMO) Professor Paul Kelly expressed a relative lack of concern on the matter, stating:

*We know that the major risk factors for long COVID are having had infection before vaccination, being unvaccinated, having severe illness and having other types of COVID that were not Omicron.[[19]](#footnote-20)*

This followed comments in September that he did not expect Long COVID to impact Australia as severely as it had in other countries, although it is not clear what this statement was based upon.[[20]](#footnote-21)

Professor Faux countered that these comments did not reflect the reality of the patients presenting at his clinic, suggesting Professor Kelly was purposely downplaying the current extent of Long COVID in Australia in order to justify the changes to public health measures, describing it as akin to “pulling the sheet over your head”.[[21]](#footnote-22)

Dr Pippa Yeoman, a sufferer of Long COVID and member of the aforementioned Facebook Group, echoed these concerns:

*He has no data on which to base those claims… He's making a political statement about how clever they were to close the borders and get everybody vaccinated and saying that means we will be different [to other countries]. If you make a claim, you need to be able to back it up.[[22]](#footnote-23)*

* The failure of the CMO to acknowledge the reality of Long COVID in Australia has concerning implications, particularly for people with disability who are already vulnerable. With the removal of mask mandates, social distancing requirements, and mandatory quarantine, the limited protection provided by vaccines remains the only line of defence against Long COVID, leaving Australians extremely vulnerable. Dr Yeoman accused the government of failing to adequately inform Australians of the true level of risk, stating:

*A sensible person who trusts the government thinks that long COVID is not within the realm of possibility for them… If I was a person who knew that if I got sick, I had a five per cent chance of having something pretty horrible, I might weigh that up in whether I get on a train without a mask.[[23]](#footnote-24)*

* The CMO’s comments have been met with sadness and anger by Long COVID patients and advocates, who feel they are being failed by a government that is neglecting to speak about the pandemic and Long COVID for reasons of political expediency.[[24]](#footnote-25)

**Australian research falling behind peer countries**

* Another serious issue in Australia’s response to Long COVID is the relative lack of research and subsequent data. Funding for research into COVID-19 is scarce, and Australia has now fallen “well behind” peer countries such as the USA and the UK, both of which have been undertaking large-scale surveys of Long COVID for some time.[[25]](#footnote-26) The UK’s National Institute for Health and Care Research has allocated more than $89 million, with studies set to investigate symptoms including brain fog and shortness of breath, the underlying mechanisms of Long COVID, and trialling possible treatments.[[26]](#footnote-27) In the USA, meanwhile, an impressive $1.5 billion has been allocated to Long COVID research, tracking and monitoring, and ensuring equitable access to support and care.[[27]](#footnote-28)
* Australian physicians and researchers have called for the government to establish its own comparable large population study to further understand the true burden of Long COVID and develop appropriate treatment protocols. At present, in the absence of good data, there are simply “too many unknowns” regarding prevention, diagnosis, and treatment.[[28]](#footnote-29)

**Insufficient funding for dedicated Long COVID clinics**

* As with funding for research, there is similarly inadequate funding for dedicated Long COVID clinics. Though clinics have been established across the country, they are “completely overwhelmed”, with patients waiting many months to be seen,[[29]](#footnote-30) in some cases up to one year.[[30]](#footnote-31) The situation is so dire that some clinics have been or will shortly be forced to close, including a “post-COVID-19” clinic at the Northern Hospital, and the Long COVID Rehabilitation Service at the Austin Hospital, which had been receiving federal funding through an agreement that ends on 31 December.[[31]](#footnote-32) At the Alfred hospital, there is a wait-list approximately 100-patients long, while both St Vincent’s and the Royal Melbourne Hospital have 11-month wait lists.[[32]](#footnote-33) In regional areas, the situation is even worse, with many patients – including many Indigenous Australians – left untreated as there are simply no services at all.[[33]](#footnote-34)
* Patients have been advised to access alternative supports through their GPs, however, there are barriers here too, as currently an individual must experience symptoms for a minimum of six months before being eligible for a coordinated care plan.[[34]](#footnote-35) Even when this care is accessible, many patients described experiences with doctors who were either ignorant of Long COVID or treated them dismissively.
* In contrast to the levels of funding being allocated to Long COVID internationally, the recently released Australian federal budget contained no provisions for Long COVID whatsoever. While $2.6 billion was dedicated to the country’s COVID-19 response, this will largely be spent on PPE and access to vaccines and treatments for at-risk cohorts. This lack of dedicated funding is disappointing, a sentiment echoed by Senator Jordan Steele-John, who stated:

*Long COVID is impacting so many in our Australian community right now — it is a debilitating illness. What is needed from the government is urgent action. That urgent action was nowhere to be seen in the budget.[[35]](#footnote-36)*

**People with disability are at greater risk**

* Both the COVID-19 pandemic and Long COVID have disproportionately affected vulnerable and marginalised populations, including people with disability.[[36]](#footnote-37) This effect has been magnified by recent decisions to remove public health provisions such as mask mandates, social distancing, and mandatory quarantine, placing people with disability at even greater risk.

**Long COVID patients unable to access disability supports**

* Perhaps the most concerning issue that AFDO would like to bring to the Committee’s attention is the inability of Long COVID patients to access mainstream disability supports, in particular the Disability Support Pension (DSP) and the National Disability Insurance Scheme (NDIS). Long COVID can be incredibly disabling, leaving individuals unable to work or complete the basic activities of daily life. In order to access the DSP or NDIS, individuals living with Long COVID must prove that they fit the detailed and stringent criteria of each – a nearly impossible task.
* While AFDO has previously criticised the DSP as being insufficient, the denial of even this meagre financial support to Long COVID patients will condemn many of them to poverty, and subsequent negative consequences for their health and every other aspect of their lives. Given that Long COVID so clearly constitutes a disability under the CRPD, to which Australia is signatory, AFDO must consider this abandonment of Long COVID patients as not only unconscionable, but a violation of international human rights law.

Recommendations

There is growing international evidence supporting the medical reality and impacts on people of Long COVID, with the costs to the individuals who have acquired this health condition and the community being significant. Yet, Australia is lagging well behind other equivalent ranked countries in terms of its research and response to the significant issues of Long COVID. Our concern is that this will continue to be the way that Australian governments operate.

AFDO endorses the recommendations of OzSage,[[37]](#footnote-38) reproduced below:

* Prevention of SARS-CoV-2 infection through all means possible is essential to reduce the long-term burden of disease and disability from COVID-19. This includes renewed efforts to raise the rates of 3rd and 4th dose boosters, and to increase vaccination rates in children. A Vaccine-Plus strategy includes safe indoor air, masks, testing and tracing, which will all reduce transmission. The combined effects of these can substantially reduce disease burden of COVID-19 and long COVID. See specific OzSAGE advice for these.
* Treatment – broader, affordable and equitable access to antivirals to decrease viral load and hasten recovery may reduce long term complications.
* We recommend the government urgently conduct modelling to assess the likely impact of long COVID on the job capacity of Australian workers, the health system, the NDIS and other disability services, and the likely demands on income support due to disability caused by long COVID. This should test best and worst-case estimates of long-term disease and disability to inform planning for the future.
* Raising awareness and acknowledgment of Long COVID and the spectrum of post-acute complications for patients and health care providers. Employers should also be made aware of the potential for increasing numbers of employees dealing with long COVID and plan for workforce issues.
* Clinical pathways and clinical decision support tools for GPs should be established for assessment, investigations and specialist referral. This includes protocols on specific diagnostics for abnormalities not detected by routine tests (pulmonary, microclots, myocarditis).
* Education for employers and organizations on pathways for medical fitness for work review and extended sick leave for staff. Occupational physicians and general practitioners with occupational interest (involving occupational therapists and neuropsychologists if needed) can clarify if an individual who complains of symptoms or is making significant errors, is capable of safe work or identify what supports are needed to maintain their role safely. The doctors can also help clarify treatment plan and the prognosis and support for return from extended sick leave if needed.
* Infrastructure to manage burden of chronic illness (specialised long COVID clinics, and health system planning for the increased burden of chronic cardiac, respiratory and other complications). Ensure specialised clinics are accessible to disadvantaged groups. This could be achieved by strategies such as outreach programs through existing health networks, upskilling regional health practitioners and ongoing support for telehealth MBS item numbers.
* Commonwealth and State and Territory governments need to plan for the potential increased demand for disability services including the NDIS in coming years . Investments should then be directed to supporting people who are disabled by long COVID to receive the necessary services and support through the health system, rehabilitation, tier 2 disability supports, and the NDIS if they experience significant and permanent disablement.
* Support for people who are unable to work or have reduced work capacity due to long COVID. Consideration of expansion of Job Access Disability support with workplace accommodations including promoting flexible working conditions, rehabilitation services, incentives for employers to accommodate workers disabled by COVID-19 (such as subsidisation of work from home equipment, supernumerary work placement) and income support for people reduced work capacity due to long COVID.

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