AUSTRALIANS AGAINST COVID

SUBMISSION: 15 December 2023

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

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. We dedicate this submission to the thousands of dead, dying and sick older and disabled people and the hundreds of thousands with Long COVID. This is a public submission.

About us:

Australians against COVID is a grassroot collective calling for COVID protections for people with disability, chronic health conditions, immunocompromised people, older Australians and those impacted by COVID. We are a small unincorporated body but our supporters include senior and well-connected people in the disability activism.

We organised last years vigil against COVID which sought to do what governments have refused to do – recognise the toll of COVID in morbidity, mortality and neglect amongst sick, disabled and immune compromised people who have now spent four years trapped in their homes due to bad policies and bad advice which values profit before public health.

We support the White Paper issued by Advocacy for Inclusion and the precautionary position of the OzSage disability working group. This submission draws on work from each and we acknowledge their work.

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. '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. It is a hamster wheel of death, disease and dysfunction accompanied by mass cognitive dissonance.

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.[1] 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.[2]
- 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%).[3]
- 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.[4]
- 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.[5]

There have been over 10 million cases of COVID in Australia.

There have been 23,766 deaths in Australia.

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[1] 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. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020

[2] 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*.

[3] 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.

[4] Lunsky, 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.

[5] 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 are approximately 4.4 million Australians living with a disability. The NDIS currently supports more than half a million Australians. 458 NDIS participants have died.

Health inequities worsen during epidemics.[6] 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.[7]

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.[8] Arguably additional disability from Long COVID is an additional jeopardy.

Governments and irresponsible public health commentators have also sought to minimise deaths from COVID by deploying diagnostic overshadowing as a tool. Deaths of COVID victims have been attributed to their disabilities. People with disabilities and underlying health conditions have also had the value of their lives diminished by public commentary which has dismissed deaths due to underlying health conditions.

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.

We are supportive of the work done by Advocacy for Inclusion which has consisted of:

- The White Paper on COVID19 and people with disability issued in August 2022
- 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
- A lengthy submission to the Long COVID inquiry

[6] 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.
[7] 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.
[8] 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.

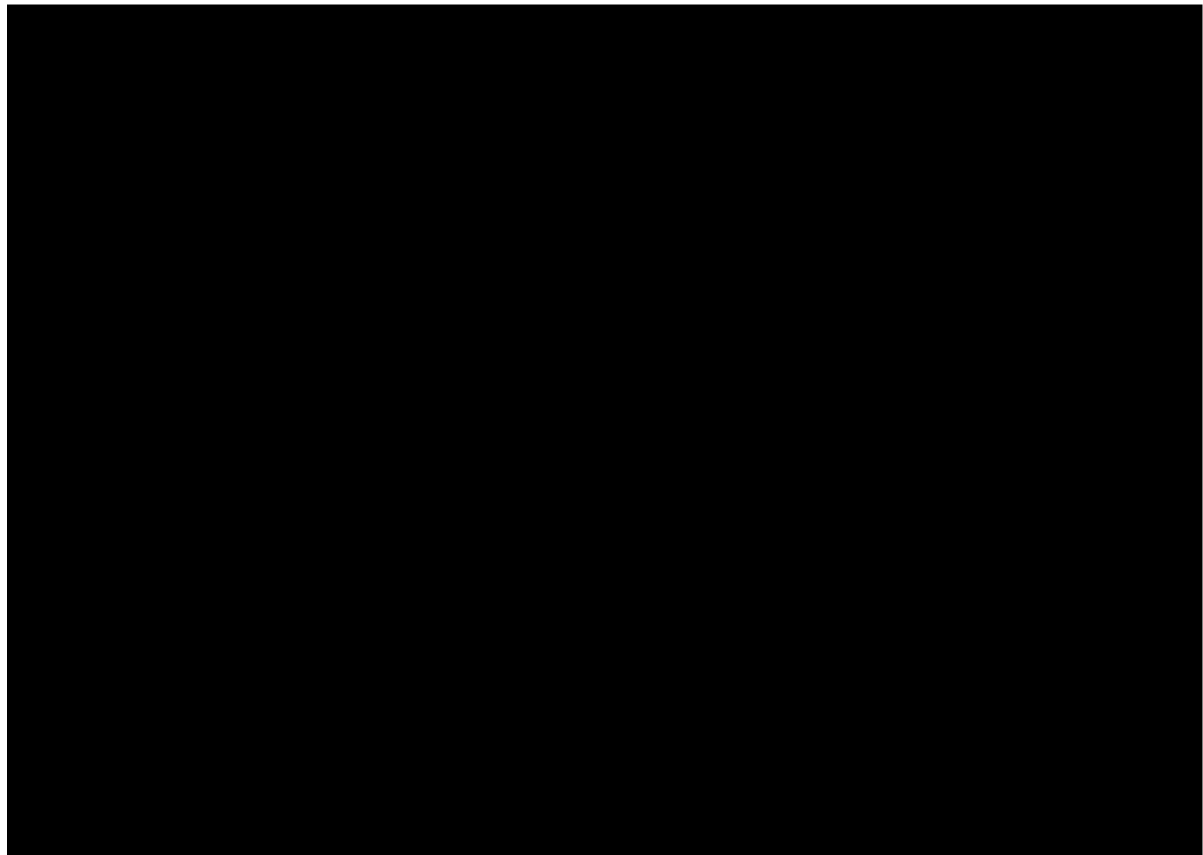
Disability in the pandemic

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:



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.

[9] 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.

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 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.

Across 2022/23 protections against COVID including masking in high risk settings and disability settings has fallen away. This has further endangered and constrained

people with disabilities. Every time a protection is removed people with disabilities are forced to impose their own protections and curtail an activity.

Where are we now

As we enter the fourth year of the pandemic the picture is grim. People with disabilities have now been trapped in our homes for four years. The practical, financial and psychosocial toll is horrific. There is an air of desperation now. People are delaying healthcare and dental work due to justifiable concerns about COVID19 as masks and other protections are abandoned in health settings. People taking meagre steps to protect ourselves, such as wearing masks are increasingly harassed and set upon. Employers are increasingly pressuring people to return to face to face venues leaving people with disabilities with a Hobsons choice – abandon employment or risk an infection. Peoples fragile social networks have gone Unlike the opening days of the pandemic no one is stepping up with supports.

Our position

- 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. People with disabilities should address National Cabinet on COVID.
- Governments need to be guided by precautionary public health principles and human rights principles, including CRPD Article 11, in managing the pandemic.
- Australians Against COVID 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.
- People with disabilities need to be the centre of these conversations just as Gay Men and substance users came to be at the centre of HIV/AIDS response's in Australia. So far this has not happened – for instance it is

disappointing that there are no visibly presenting disabled people on the COVID Inquiry, despite disabled people being the most effected in the pandemic.
- 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. Effectively they told disabled people to shield and isolate on our own as the trade off for reopening businesses. In shielding people with disabilities have been the system savers of the pandemic = preventing ICU's from being overrun by sick people with complex disability access and support requirements that hospitals are unable to deal with.
- Having done our part in a difficult set of circumstances for four years we require Governments to reciprocate with actions, policies and modes of delivery that enable people to survive and carry on.
- There are urgent priorities for Governments to ensure that people with disabilities are supported, protected and treated with fairness and decency in pandemic circumstances. We agree with AFI's priorities which are listed at Attachment A
- We want:
    - A public commitment from all governments to end the current uncontrolled transmission of Covid in Australia through clean air, masks, distancing and sensible health measures.
    - We seek guaranteed rights to work, study and operate from home, essential COVID safe spaces, supports, including rehabilitation, NDIS access and income support, for people with Long COVID
      All services, consultations, transactions and processes that are available face to face should also be available online while uncontrolled
    - We seek community development work and practical support for the isolated
    - Better access to RATS, PCR's and free masks and HEPA filters.
    - Masking and protections in all health and disability settings

We are not calling for lockdowns but sensible protections and inclusion measures that provide a pathway to living again for people at risk of serious illness.

The current living with COVID policies are failing Australians. The vaccines are great but they are not yet enough. Barring significant medical advances COVID will never be normal and never be endemic and Australia must change course.

Please feel free to discuss this submission with us - Craig Wallace (M: [redacted] [redacted] and Sam Connor (M: [redacted]

Regards

Craig Wallace and Sam Connor – Convenors

Attachment A

Priorities for people with disabilities in the ongoing COVID pandemic

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

- Reponses 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 includes 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