



Sick, Sad and Shut in – COVID 19 and people with disability – an AFI Forum held on 2 September 2022

What we heard

Shared statement

On 2 September 2022 more than 50 people working in disability, health policy and advocacy came together in a public forum to offer reflections on the management of the ongoing pandemic.

As thought leaders at the intersection of disability, health and COVID policy we were pleased to lead discussion in the forum, to offer our endorsement of the Advocacy for Inclusion [White Paper on COVID](#).

As the White Paper is finalised we urge Governments to adopt its recommendations to ensure that the rights, health and welfare of people with disability are centred in the management of the pandemic from this point. We specifically urge Governments to centre the human rights of people with disability in responses as Public Health emergency orders are modified or lifted. While this statement is issued in the ACT there are lessons for all States and Territories and the Federal Government.

We can't go on like this. Governments must start listening to people with disability.

We endorsed the four key priorities for action:

1. Preventing disease and death among people with disability;
2. Providing healthcare to people with disability diagnosed with Covid-19;
3. Preserving rights, supports, access and inclusion during the pandemic; and
4. Learning lessons to do better.

We invite Governments to reflect on the feedback received in the What We Heard report that follows this statement. Some clear messages were delivered:

1. Current approaches to managing COVID are unfair and impose inequitable burdens upon people with disability – this is not the hallmark of a decent society.
2. A political narrative emphasising personal responsibility is inadequate and problematic
3. The impacts of COVID are having compounding consequences on the quality of life of people with disability – we can't go on like this
4. Measures identified in the white paper will prevent a cascade of negative consequences
5. We know what works and we need politicians to summon the political will to make necessary changes and to prioritise the most vulnerable;
6. Stresses on the disability community are acute but the issues raised go well beyond us
7. Australia is a signatory to the UN Covention on the Rights of People with Disability and has obligations consequential to Articles 11 and 25 of CRPD

Tomorrow the ACT Government is scheduled to end the declared public health emergency and make a COVID-19 Management Declaration. Changes will include a scaling back of some measures in disability settings including vaccination requirements.

Today we again highlight the need to centre people with disability in the pandemic with actions to ensure access to supports, treatments, COVID safe health care and an inclusion guarantee which recognises, validates and responds to the needs of people continuing to shield.

None of us are calling for lockdowns in the present circumstances – but we are ask for sensible protections and inclusion measures for people with disability. COVID is not over and we urge Governments to listen and attend to the continuing cascade of consequences described by participants in the forum

Signed by:

Sam Connor, President of People with Disability Australia

Corinne Dobson, A/g Chief Executive Officer Mental Health Community Coalition ACT

Dr George Taleporos, Consumer Advocate, Department of Health COVID-19 Disability Advisory Committee

Craig Wallace, Head of Policy, Advocacy for Inclusion

29 September 2022

What we heard

Introduction

On 2 September 2022, Advocacy for Inclusion incorporating People with Disabilities ACT (AFI) held a public forum to discuss our new draft policy white paper. The paper provides an overview of AFI's policy position regarding COVID, and is the first in a series of position papers which centre, reflect, and amplify the experiences and voices of people with disability.

The forum, *Sick, Sad, and Shut in? Life with COVID for people with disability*, brought together over 50 attendees including members, advocates, government officials, allies and the public.

AFI's Head of Policy, Craig Wallace, present the current draft of the white paper. This presentation identified four key priorities for government action, including:

1. Preventing disease and death among people with disability;
2. Providing healthcare to people with disability diagnosed with Covid-19;
3. Preserving rights, supports, access and inclusion during the pandemic; and
4. Learning lessons to do better.

The ACT Minister for Health, Rachel Stephen-Smith MLA, subsequently accepted and responded to the white paper, before five panellists were invited to discuss the complex policy environment regarding COVID, and its ramifications for the disability community.

The panel consisted of:

- Sam Connor, President of People with Disability Australia
- Anna Davidson, Director of the Port Stephens GP Super Clinic and OzSAGE member
- Corinne Dobson, A/g Chief Executive Officer Mental Health Community Coalition ACT
- Dr George Taleporos, Consumer Advocate, Department of Health COVID-19 Disability Advisory Committee
- Craig Wallace, Head of Policy, Advocacy for Inclusion

The forum was facilitated by prominent Canberra journalist Genevieve Jacobs, Group Editor of Region Media.

Throughout the forum, audience members were invited to ask questions of the panel and participate in the online chat. This report provides a preliminary outline of the key themes discussed by both the panel and the audience.

Discussion

Five key themes emerged from the discussion at the forum. They are summarised as follows:

1. Current approaches to managing COVID are unfair and impose inequitable burdens upon people with disability – this is not the hallmark of a decent society.
2. A political narrative emphasising personal responsibility is inadequate and problematic
3. The impacts of COVID are having compounding consequences on the quality of life of people with disability – we can't go on like this
4. Measures identified in the white paper will prevent a cascade of negative consequences
5. We know what works and we need politicians to summon the political will to make necessary changes and to prioritise the most vulnerable; and
6. Stresses on the disability community are acute but the issues raised go well beyond us.
7. Australia is a signatory to the UN Convention on the Rights of People with Disability and has obligations consequential to Articles 11 and 25 of CRPD

Widespread impacts

Many of the forum participants highlighted the inequitable impacts of current policy approaches to the pandemic for people with disability. However, as underscored by several panellists, the issues raised in the white paper are not only relevant for people with disability. Rather, the issues affect “a whole range of people. It’s 41% of Australians. That’s the people who have had cancer, that’s people who have had heart conditions...”¹ and that’s the people who experience other intersectional disadvantage, such as those from culturally and linguistically diverse backgrounds. Moreover, as noted by one panellist, these issues are relevant for the families of at-risk individuals.²

Audience members supported the panel’s remarks, as participants with cancer or with unwell family members reflected on their own challenging experiences under current policies. For example, one audience member recounted the experiences of their daughter, who was unable to participate in education and was now experiencing loneliness. Similar personal narratives were shared by other forum participants, and demonstrated that the issues raised in AFI’s white paper are pertinent to a significant number of Australians. In this way, the forum showed the widespread detrimental consequences of existing COVID management practices in Australia.

The inequitable burden of COVID

Noting the widespread impact of pandemic, the forum discussion highlighted an erosion of solidarity over time regarding the management of Covid-19. It was argued that this has, in part, contributed to the inequitable burden imposed by the current policy landscape for people with disability. These burdens have consequences above and beyond the physical health of individuals. As one panellist noted, mental health impacts are disproportionality effecting the wellbeing of people with disability, and there are significant and ongoing consequences on people’s quality of life.

One audience member spoke to the inability of their daughter to participate safely in education, and the loneliness that they are experiencing. Another spoke to the inability of their child to safely participate in driving lessons.

Personal responsibility – a troubling ableist narrative

We discussed the rhetoric around personal responsibility for Covid-19. This discussion was two-pronged. First, forum members felt that personal responsibility was often mobilised as an alternative to protective measures. In turn, community opposition to lockdowns was frequently used to argue against the nuanced and sensible measures being proposed by the disability community. The white paper calls for sensible measures which address institutional and structural factors, and which include measures aimed to reduce transmission. It does not call for lockdowns.

Second, it was noted that people with disability *are* taking responsibility for their health and this has been a system saver for an acute health system which – in the absence of a fully realised Disability Health Strategy – would not be able to cope with a significant influx of people with disability.

A lack of structural responsiveness left people without options and without the tools to make their own risk assessments. This tension resulted in detrimental consequences for people’s mental health and wellbeing. As a result, personal responsibility was not considered to be an adequate or realistic policy response.

Forum participants highlighted that governments must improve ventilation in public spaces, legislate for air quality, and invest in the creation of safe spaces in environments such as health and recreation. Currently, these initiatives are the responsibilities of individuals and/or organisations, which do not receive additional funding.

¹ Sam Connor

² Anna Davidson

The cascade of consequences

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.

Finally, as discussed above, the impacts of COVID are having compounding consequences on people’s quality of life. Individuals who are unable to safely participate in society are unable to pursue their human rights, and young people are falling behind their peers. These consequences will continue to cause significant economic, social and cultural harm, unless measures which aim to reduce uncontrolled transmission are implemented.

We know what works

The overwhelming perspective of the panel was that we know what works, “we have all the tools...”, but there is a lack of political will to make necessary changes. The forum provided a comprehensive and passionate overview of the issues at hand. It called for measures which address the institutional and structural barriers to quality of life, which are arising from existing Covid-19 management practices. Many of these recommendations are covered in AFI’s white paper, and comprise actions to reduce transmission. They include:

- Legislating for air quality measurement and cleaning;
- Investing in safe spaces, such as in health care as a priority;
- Measures to restore social inclusion amongst shielders;
- Guarantees of non contact access to work, study and social participation;
- Increased transparency and inclusion of the disability community in decision-making on Covid-19 policy;
- Improving ventilation in public buildings; and
- Introducing and/or maintaining mask mandates where appropriate.

About Advocacy for Inclusion

Advocacy for Inclusion incorporating People with Disabilities ACT³ is a leading independent organisation delivering reputable national systemic advocacy informed by our extensive experience in individual advocacy and community and government consultation. We provide dedicated individual and self-advocacy services, training, information and resources in the ACT.

As a Disabled People's Organisation, the majority of our organisation, including our Board of Management, staff and members, are people with disabilities. Advocacy for Inclusion speaks with the authority of lived experience. It is strongly committed to advancing opportunities for the insights, experiences and opinions of people with disabilities to be heard and acknowledged.

Advocacy for Inclusion operates under a human rights framework. We uphold the principles of the United Nations Convention on the Rights of Persons with Disabilities and strive to promote and advance the human rights and inclusion of people with disabilities in the community. Advocacy for Inclusion is a declared public authority under the Human Rights Act 2004.

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Advocacy for Inclusion acknowledges the Aboriginal and Torres Strait Islander peoples as Traditional Custodians of the lands where we live, learn and work. We respect and celebrate the diversity of individuals, including those amongst the lesbian, gay, bisexual, trans, and intersex communities and we value and promote inclusion and diversity in our communities.

³ On March 24, 2021, Advocacy for Inclusion (AFI) officially merged with People with Disabilities ACT (PWDACT), a systemic advocacy organisation based in the ACT. 'AFI' also acknowledges the values and philosophies of PWDACT.

