Commonwealth Government COVID-19 Response Inquiry

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Submitted to:

The Independent Panel
Appointed by PM Albanese
COVID-19Inquiry@pmc.gov.au

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Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families and kin, formed in 2002. Our ‘friends’ include more than 6000 people with lived experience of mental health concerns, including suicide and suicidality, across Australia. We recognise that some of our ‘friends’ network includes veterans and their families. All members of our Board and staff have mental health lived experience as either a consumer, family carer or both. This is core to our advocacy, recognising that the impacts of policy and practice are felt not only by individuals, but also by families and whole communities.

Our core business is to advocate for effective policies and systemic change to improve mental health care, services and support across the whole Australian health and social care system, including within State and Territory jurisdictions.

We welcome the opportunity to provide our feedback to this crucially important national issue.

Purpose and Scope of this Inquiry

The purpose of the Inquiry is to identify lessons learned to improve Australia’s preparedness for future pandemics. The Inquiry will review the Commonwealth Government’s response to the COVID-19 pandemic and make recommendations to improve response measures in the event of future pandemics, to more effectively anticipate, adapt and respond to pandemics.

Our Response

Our submission and evidence most relates to ‘**Mechanisms to better target future responses to the needs of particular populations**’ within the Inquiry’s terms of reference. We wish to focus on the experiences and needs of three distinct populations within this submission:

1. People with complex mental health conditions and/or psychosocial disability, in general
2. People with complex mental health conditions and/or psychosocial disability, in particular, who reside in supported residential facilities in the community (otherwise known as hostels).
3. Family, carers and kin of people with mental health conditions.

People with complex mental health conditions and/or psychosocial disability

In October 2022, our submission to the Inquiry into Long COVID and Repeated COVID Infections highlighted our concerns that people in this population group are less likely to be asked about COVID vaccination, physical health concerns related to COVID more broadly, and also asked and have impacts of Long COVID detected and addressed. We argued that there are likely 3 key reasons for this:

- Systems of care that hold fatalistic attitudes towards people with mental health conditions about their physical health, particular people with more severe mental health conditions like schizophrenia.
- Diagnostic overshadowing whereby people’s physical health concerns and help-seeking for those concerns are overlooked and dismissed, with primacy of focus on mental health clinical symptoms and their treatment with psychiatric medications.
- Discrimination and stigma toward this population about their capacity to understand their health, have health literacy and be able to improve their health and quality of life.

Our survey of 512 consumers and carers from across Australia[1] found that they have high rates of COVID vaccination, but a significant minority are not asked about their vaccination status by their GP, nor about their physical health, including screenings for detection and monitoring of several major chronic conditions and risk factors, and immunisations, generally.

Recommendation: Consistent, national guidelines for primary care and other health professionals must acknowledge this population within a framework that addresses the potential for overt and covert forms of discrimination on the basis of mental health.

People with complex mental health conditions and/or psychosocial disability who reside in supported residential facilities (SRFs)

In 2020, we raised concerns with the South Australia Office of the Chief Psychiatrist, The SA Health Minister and the SA Attorney General's Department about the **COVID-19 Emergency Response Act 2020 – Schedule 1** [2]. I was the lead SA Mental Health Commission during 2020-2021. LEA also raised this situation in December 2020 in our later submission to Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. We were aware that similar measures were in place in other jurisdictions, though concern from within the states/territories and national advocacy sector was largely silent, despite evidence of clear human rights concerns.

The SA COVID Emergency Response Act was enacted in April 2020 in response to concerns about COVID-19 and compliance with social distancing by residents of Supported Residential Facilities (SRFs). It put in place measures to restrict an individual's movements where there is a clear risk that they may contract or contribute to the spread of COVID-19.

Evidence of need for the Act was largely absent. In my discussions with the Public Advocate, she explained that the legislation was enacted because the Crown Solicitor was concerned that people not be detained unlawfully; that the legislation was primarily a preventative measure. This response seemed completely disproportionate when compared with the response to other sectors of the community. It also seemed completely disproportionate when compared with the evidence of need. My understanding was that there have been only 2 occasions where the COVID Act was used and these occurred quite early in 2020. One instance related to a resident of a RACF with behavioural issues wandering with no clothes on, which may have been unrelated to any concern about COVID, and the other instance involved a person in an SRF where staff struggled to prevent the person from going out, despite their efforts.

For brevity, I have summarised a range of other more specific concerns below:

1. The COVID Emergency Response Act was enacted with no apparent consultation with the mental health sector, despite many people with significant psychosocial disability being residents in SRFs. The Chief Psychiatrist, the Mental Health Commissioners, and advocates for people with mental health conditions were not consulted. Their views would have provided valuable insights.
2. The Act was not aligned with the United Nations Convention on the Rights of People with Disabilities; nor was it clear how it aligned with SRF regulations and policies regarding use of restraint, or NDIS policies.
3. Features of the Act appeared to be far too 'loose' and open to potential abuse of power by SRF providers or delegated others. There also appeared to be very little in terms of procedural safeguards and arrangements for effective oversight to ensure that residents were protected from improper or unjust exercise of these powers that have the effect of interfering with fundamental human rights. This was of particular concern for SRF residents who were most at risk of abuse, neglect, violence and exploitation without sufficient safeguarding and monitoring of the use of this mechanism. These same people do not have equitable access by way of their disability to complaints and other mechanisms on which the legislation relies to allow recourse for individuals.
4. Features of the Act offered no real or timely mechanism for appeal. In terms of review of decisions, I note that an application must be made within 7 days. This short time limitation rarely protected a person and often worked against their interests, e scheduling of review being so far ahead that the appeal process was noted as meaningless anyway.
5. The power to detain persons in the SRFs was conferred without adequate safeguards. This posed a significant risk that residents will be detained arbitrarily, which constituted a violation of rights and liberties protected under human rights law. Similarly, while the legislation talked about external

oversight from the Community Visitor, I understand the Community Visitor was not authorised to enter a person's place of residence.

6. The legislation appeared to enable persons without any medical training (or any training) to determine mental incapacity and, more concerningly, to physical detail and restrain SRF residents to their rooms. Schedule 1, Clause 11 allowed person(s) in charge of an SRF, or a manager of the service provider organisation to be known as the prescribed person to seek approval for the temporary detention (restriction of movement) of a protected person up to 28 days. The level of power the legislation afforded the prescribed person and lack of oversight in how powers were used, was also concerning. A level of independent oversight was needed.

Overall, the response within SRFs appears to have been one largely of containment, with little attention to the mental health and wellbeing impacts for residents and staff. These facilities arguably are home for people who are among the most marginalised, isolated and disconnected from community despite SRFs being 'in the community'; however, there was virtually no direct support for their mental health and wellbeing needs during COVID, or increased resourcing to support the care needs arising from COVID within these settings.

Underlying the response, as enabled by the COVID Act, seemed to be a range of assumptions about the capacity of people who live in SRFs to understand health information, follow rules, make decisions about their behaviours, and so forth. Justifications for the COVID Act appear to assume that they had no capacity at all. This is simply not the case. There are many people in the community who we could argue have varying degrees of capacity to follow rules and make correct decisions, yet they were not subjected to the level of response and threat of restrictive practices imposed on SRF residents. For many people who live in institutionalised settings like SRFs, the right to make basic decisions, to express choices about what one wears, eats, watches on TV, etc is already severely restricted.

<u>Recommendation:</u> Hence, we urge the Independent Panel to consider our Australia's responsibilities as signature to the CRPD are considered in the event of future pandemic events. Stigma and discrimination emerge quickly during crises, and the assumptions made about the SRF population saw some of the worse elements of this being legitimised.

Family, carers and kin of people with mental health conditions

LEA had the pleasure of being a key collaborator on a research project by exploring the experiences of mental health carers during the COVID-19 pandemic: **'Mental Health Family Carer Experiences of COVID-19 in Australia'**. The research was conducted by Associate Professor Melissa Petrakis and Caroline Walters from the SWITCH Research Group at Monash University, in collaboration with the National Mental Health Consumer Carer Forum (NMHCCF). As a member of the National Mental Health Consumer and Carer Forum, LEA's Executive Director was on the Steering Committee and provided facilitation to some of the data collection and analysis, review of report and publications, and delivery of the presentation of findings to the sector and community. The project was funded by National Mental Health Commission. The SWITCH research team recently won a national award for its collaborative work on this project.

This research made a number of recommendations to Government to address the needs of mental health carers during events like the COVID pandemic, should they recur. These are summarised below, with further detail available in the report [3].

<u>Recommendations:</u>

In the short-term, the Australian Government:

1. Review practices in inpatient and other clinical settings to ensure family inclusion and partnership in supporting people with mental health challenges.
2. Fund the creation of carer peer navigator roles – providing information and support – across inpatient and community services for families, carers and supporters.

3. Prioritise the creation of carer on-call roles, accessible via local and regional mental health triage services, to respond to crises experienced by families.
4. Fund available and responsive mental health carer respite to ensure carer workload does not overwhelm family members so they are able to remain in paid work.
5. Respond to current and future major disasters (pandemics, fires, floods, and drought), and create local and regional mobile centres for family assistance.

In the long-term, the Australian Government:

1. Fund diverse modalities of consultations and therapeutic interventions to enable mental health consumer and carer choice, inclusive of but not defaulting to teleHealth.
2. Recognise the risk inherent in providing long-term and acute mental health care on carers, and establish domestic violence services tailored and responsive to family members experiencing acute and/or cumulative risk and violence.
3. Recognise the impact of providing long-term and acute mental health care on the psychosocial wellbeing of carers, and establish suicide prevention services responsive to family members experiencing acute and/or cumulative stress and distress.
4. Establish funded family-carer collaborative hubs to foster, mentor and disseminate family leadership in service redesign, evaluation and research.
5. Provide national guidance and co-ordination for innovation across all states in administration and guardianship as it relates to mental health carers concerned about the safety of loved ones in their absence or upon their death.

Contact

We thank the Independent Panel for the opportunity to put our views forward. We wish you well with the next steps and would be keen to contribute our lived experience perspectives to any future discussions about this important topic.

Your sincerely

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