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Productivity Commission

Final Review of the Mental Health and Suicide Prevention Agreement

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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 11,000 people with lived experience of mental health concerns across Australia. This includes lived experiences with all parts of the mental health care system, NDIS, psychosocial disability support outside the NDIS, PHN commissioned services, public and private service options, and service provision across urban, regional, rural and remote Australia. All members of our Board and staff have mental health lived experience as either a consumer, family/carer/kin/supporter, or both.

Lived Experience 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 and psychosocial disability support services and support across the lifespan, 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 Final Review of the Mental Health and Suicide Prevention Agreement.

Background

The National Mental Health and Suicide Prevention Agreement establishes a framework for reform of the mental health and suicide prevention system; this framework operates alongside commitments made under the National Health Reform Agreement and the National Agreement on Closing the Gap that affect mental health and suicide prevention outcomes. It identifies priority areas for action within the mental health and suicide prevention system, including enabling a whole-of-government approach to services, several data improvements and consistent evaluation.

In addition to establishing a vision and identifying priority areas for reform, the Agreement sets out the roles and responsibilities of the Australian, state and territory governments within the mental health and suicide prevention system and includes accountability and reporting mechanisms to monitor progress. Bilateral agreements, signed by the Australian Government with each state and territory, complement the Agreement with a suite of commitments for localised collaborative efforts and funding transfers.

Purpose of this Consultation

The Australian Government has asked the Productivity Commission (PC) to undertake the final review of the National Mental Health and Suicide Prevention Agreement. In particular, the PC is keen to hear about perspectives on the effectiveness of programs and services delivered under the Agreement as well as the way governments work to achieve the goals of the Agreement.

Our Responses to the Review

We reached out to our 'friends' network to hear their perspectives, which we have provided here, as they were given to us for this submission. We asked them 4 general questions about whether services had improved. Responses were mixed. Below is a selection of responses across a range of mental health system issues.

1. How well are services meeting your needs?

Some reported that the sector had improved locally for them:

> "*Community mental health, the XXX Centre has improved its model of care; or at least the workers there this time listened, affirmed, and were recovery focused and empowering. Hospital was less*

> *restrictive in practice; more generous leave policy. My carer said they had probably learnt since covid how locking someone away from the world and usual community supports is not helpful*." NSW Consumer

However, many reported that little had changed, and some experiences of care had worsened. These included options that effectively met ongoing and unmet needs, problems with costs, system navigation and access to care:

> "*It's completely out of balance. There is so much focus on crisis and acute care. But a lot of that is just moving people around the system and not offering support to prevent further problems or improving overall wellbeing in the longer term. There is significant unmet need still in the community for people with enduring mental health support needs and the service models that currently dominate don't cater to their ongoing needs. Everyone is pushed through the same short-term processes as if their circumstances are all the same. But only those who have more ability to navigate and engage with these offerings benefit ultimately from this type of system*." SA Consumer

> *"We are not recognising significant reasons why people do not seek help. We are not addressing the underlying causes of mental ill-health and suicide in people's lives, or offering solutions or enough support to address the contributing factors like family violence, abuse, unemployment, addiction, etc."* NSW Consumer

> *"We have risk averse, hasty procurement processes that have also resulted in wildly anti-competitive behaviour - the same tenders going to the same (historically religious, historically clinical) providers with no regard for the diversity of the communities these services are being established in."* QLD Consumer

> *"I would consider myself well-resourced (I work, my husband is an amazingly supportive carer/partner, I have an excellent GP and psychologist) - but the number of psych sessions per annum that are supported by Medicare is ridiculous. I have reduced my support multiple times due to gap fees and running out of Medicare-supported sessions - particularly since changing from a full-time role in nonprofit to working for myself. My work exposes me to all sorts of people seeking (or considering) mental health support services and their experiences are almost always worse than mine. Finding an available psych, having the money for gap fees and then running out of sessions each year is common experience - and the financial strain stops so many people from getting help."* Consumer

> "*I'm a peer worker in a community mental health rehab and have also worked on an acute ward in SA health. As a past service user and now from seeing it from the inside, there are so many gaps, unmet needs and quite a toxic, stigmatised culture (especially in acute). For people to really get the help they need from these services, there needs to be MUCH more follow up support, less focus on the medical model and a huge overhaul of the culture that discriminates against people with mental health conditions. There was a real 'us vs them' in acute, a hierarchy and people with unmet needs being discharged far too quickly and then just coming back over and over. It's a complete mess. In community it's a better story, its recovery focused from mainly allied health. More community rehabs are needed. Lived experience is behind the times in the public system and needs to get with the program, it's so important for us to be heard and valued*." SA Consumer

> "*Not very well. A lot of the time I can't afford the services that they offer. Or there's an extensive waiting list to see someone. I've had a Mental health plan but once they hand it to me, they never ask about it again. Also, not happy as another problem I've noticed is a lot of handballing from services*." Consumer

> "*As a DFSV [Domestic Family & Sexual Violence] Victim-Survivor with regular, daily symptoms similar to undiagnosed PTSD, I have found that the DFSV specific services in Tasmania have been very beneficial and, in the majority, professional, responsive and trauma informed. The same cannot be said for the Tasmanian cohort of Mental Health services, including Tassie based consumer and*

provider representative agencies which fail to recognise the trauma associated with DFSV unless the person has a mental health diagnosis and has engaged with the hospital or psychiatric systems. The short- and long-term mental health and physical effects of DFSV on victim-survivors is well documented but it would appear that Tasmanian Mental Health agencies either never 'got the memo' or simply chose to ignore it in favour of those consumers who have psychiatric or hospital experience. Any future funding provided to these services via grants or from local/federal government for future and/or services should be dependent on them being able to demonstrate their ability to professionally deal with and understand the complexities of trauma violence informed care (TVIC) and ensure that the rising number of DFSV victim-survivors with mental health needs are catered for promptly, confidentially and safely. I am not seeing this in the Tasmanian Mental health consumer representative agencies I have been involved with. In fact, the complete opposite has held true." TAS Consumer

"*They [mental health services] are poor in still responding to the processes of immediate danger…from over the last ten years ago, not much has changed…GPs are the initial forefront and lack of resourcing in all areas is still not adequate for people still sitting in Hospitals waiting and Triaged, whilst if the person(s) leave, the duty of care is 'a-washed' by the Hospital. This is still happening and in desperation, due to the lack of care, people do take their lives*." Consumer

2. Have you noticed any service improvements over the past 3 years?

Likewise, when asked about any improvements, people who spoke to us struggled to identify any:

"*I've seen more contracts be awarded to split groups and nonprofits being managed poorly. I've seen more lived experience roles be managed poorly - there are increasing numbers of them, poor contract management when multiple teams are working together in a hub, poor understanding of trauma-informed practice and trauma-informed support and leadership to those roles within organisations are just some of the issues."* Consumer

"*I felt like it was getting worse in all aspects*." Consumer

"*There is a lot of rhetoric. Some agencies are showing some development, with Head to Health in XXX [VIC]."* Consumer

3. What have been your best experiences of services as a carer?

Mental health family cares continue to see little improvement from their perspective. The mental health system continues to treat families and the fallback position for support when systems fail and people fall through the gaps in services. Coordination of care continues to be largely unrealised and service-centric rather than person-centred.

"*Woeful, invalidating, shameful, elitist and negligent*." VIC Family Carer

4. How well are services meeting the needs of the people you provide care and support to?

"I don't believe very well. I just believe for mental health there's to many waitlist. And when you trying to care for your mentality Ill family member you just feel helpless." Family Carer

"*Some are trying hard, funds stifle it, people in Agencies are trying, but are influxed by many different cohorts."* Family Carer

Further Comments

In general, the Illness framing of the Productivity Commission's review is problematic and has the potential to reinforce the dominance of narrow clinical models that are part of the problem and that have stifled more holistic models that acknowledge the reality of diverse social determinants that impact mental health and wellbeing.

The Need for More Investment in the Lived Experience Workforce

Some of our 'friends' network noted that there was progress particularly with the growth of the Lived Experience workforce though there is still a long way to go to achieve consistent federal and jurisdictional support, and significant cultural challenges that need to be addressed recognise the value of this workforce, achieve equity alongside other disciplines, and address system cultural inertia and understanding of the value of this workforce. Of note, much of the progress and innovative activity (such as frameworks, checklists, guides to embedding Lived Experience) have been initiated by the Lived Experience community tired of waiting for federal and state/territory jurisdictions to support them. This has led to a proliferation of highly committed efforts that now require strategic structural support to more fully impact sustainability and translation at scale for more meaningful improvement to the mental health system.

There has been some funding support shown (e.g. federal funding support to establish a national mental health consumer Peak and national family/carer Peak; recent federal announcement of 2-year seed funding to support the establishment of a National Mental Health and Suicide Prevention Lived Experience (Peer) Workforce Association; the Aboriginal and Torres Strait Islander Lived Experience Centre (known as ILEC) supported by the Black Dog Institute; the Carer Lived Experience Workforce (CLEW) network supported by TANDEM – the Victorian Lived Experience Peak for mental health family/carers). However, some hugely valuable initiatives such as the Centre for Mental Health Learning (CMHL) which is the central agency for public mental health workforce development in Victoria have had funding removed; and others have been subject to precarious funding which has hampered their sustainability, or remained grassroots initiatives whose enormous value has not been realised and supported, particularly those working with more marginalized parts of the community.

The Need for Clearer and More Timely Evidence and Evaluation

It is unclear whether many of the initiatives that have been introduced within the past few years have actually led to improved outcomes, or whether the service models being rolled out have evidence of meeting need, as many are not properly evaluated (eg. Headspace). Many haven't allowed lived experience-led service models to emerge, and few lived experience-led programs have been rigorously evaluated (eg. Safe Havens, Family Carer programs, street-front AOD and homelessness programs, grassroots cultural diversity services). It is unclear whether some of the more politically 'popular' models being implemented (eg. Digital) have been evaluated. There is a sense that some programs are being introduced en-masse without sufficient time to adapt them to the local needs of the jurisdictions and understand how they are impacting locally. A cookie-cutter approach to rollout seems to be the norm.

The Potential for Inequity is Growing, Not Reducing

We are concerned that many of the new services and models of care are not reaching those most in need. There is the potential for these models to broaden the inequity gap of unmet need, with some groups of people in need of support sitting completely outside of the systems in which these types of supports operate. Many of these models require the person to find and go them, rather than reaching in to where people live in the community. Many rely of narrow assumptions about help-seeking that simply do not match the reality for many. We encourage you to look closely at the outcomes and lessons learned from the ACDC Project https://acdc.org.au/ .

There is also concern for growing inequity between the states and territories, with some jumping ahead due to greater investment, greater resources, geography that enable them to offer more efficient services at scale, and other factors. The peer workforce is one example where thin markets, workforce retention issues, lack of access to sufficient training and support, in some jurisdictions like the Northern Territory and Tasmania, and rural and remote regions of several states (eg. SA, QLD, WA) have the potential to lead the structural inequities in access to new innovations and also existing best-practice programs.

Governments seem to have become distracted by ‘shiny new buildings’ where people can go to in order to seek help for their distress. But there are many with unmet needs who simply will not walk through these doors for a broad range of reasons related to the nature of the mental health challenges, stigma, self-stigma, fear, shame, physical health conditions that prevent them from access, communication needs that are not recognised or catered for when they get there, and so forth.

As a consequence of investment in certain models (often expensive and not properly evaluated before mass rollout), some groups within the population have been left behind. One example is the very old with mental health conditions (see McKay et al. Australasian Psychiatry, 2024, DOI: 10.1177/10398562241290031 which was a collaboration with LEA). This project involved descriptive analysis of changes in access to Better Access by people aged 75–84 and over 85 using data analysed and published by the AIHW. It found that, since the introduction of Better Access, rates of access to specialist inpatient and community mental healthcare have reduced for those aged 75 years and older. The reduction is greatest for those aged 85 and over; with a 21% fall in community care access, 54% fall in inpatient access, and Medicare-funded psychologists and clinical psychologists access failing to rise above 1%. Rates of admissions by those 85 and older to inpatient care without specialised mental healthcare have increased by 92%, with emergency department presentations with mental health problems increasing by 33% since 2014–2015. From these results it is clear that the oldest people in Australia have missed most benefits from mental healthcare reforms. The contribution of these changes to high rates of mental illness on entering residential aged care, persistent high suicide rates in older men, and increased use of emergency departments and general hospital beds demands further inquiry and action.

Concerns about NDIS and Unmet Need Remain Unresolved

The perverse organisation behaviours of mental health services as a result of the introduction of NDIS has to stop. This includes the many examples of people being discharged from clinical mental health services once they get NDIS support. There continue to be many people with significant psychosocial disability who do not receive NDIS, do not or cannot engage with the process of applying for NDIS despite being eligible. NDIS is also extremely limited in its focus beyond basic support; its workforce is largely not mental health trained.

Generic Versus Place-Based Approaches

There hasn’t been sufficient community oversight of the rollout of past Agreements. This has just brought out tensions when there has been a lack of funding flexibility to allow partnerships across the system. Instead, it has created short-term cycles of competitive contracting, especially between Community Managed Organisations. This has been particularly problematic in regional and rural communities that have seen services and providers come and go (winning and losing contracts). This has also meant that there has been little flexibility or sufficient time to roll out place-based models that actually adapt to the local circumstances, provide long-term security for their workforces, or seek community input to inform and design those models locally. Further impacts have been that it has been extremely difficult for researchers to engage rural services, given these uncertainties and pressures, so much needed evaluation and testing of innovations is made more difficult in rural areas. There's been a rush to rollout a large number of centres based around new models, which has also meant the need to rapidly establish workforces in areas that may not have capacity to source, train or retain them, and a lack of time spent to build relationships with the community itself and understand what they actually need.

Coercive Treatment and Use of and Variation in Use of Involuntary Care has not Reduced

Rates of Community Treatment Order (CTO) use and variation in CTO use continue to vary significant across, between and within state and territory jurisdictions. The reasons for this remain unclear. The disproportionate use of CTO with some populations has continued. LEA is currently involved in a large national ARC-funded project examining this variation across SA, VIC, NSW and QLD drawing on AIHW reportable data and administrative data from the jurisdictions. AIHW data has shown that, for 402,060 individuals who were in contact with specialist mental health services, 51,351 (12.8%) were receiving compulsory community treatment. Percentages varied from 8% in NSW to 17.6% in South Australia. There were also wide variations within jurisdictions. In NSW, prevalence ranged from 2% to 13%, in Victoria from 6% to 24%, in Queensland from 11% to 25%, and in SA from 6% to 36%. People who were male, single and aged between 25 and 44 years old were significantly more likely to be subject to compulsory community treatment.

Contact

We thank you for the opportunity to put our views forward. We wish you well with the next steps and would be pleased to contribute our Lived Experience perspectives to any future discussions about this important topic.

Your sincerely

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