Consumers Health Forum of Australia

SUBMISSION

Select Committee on Mental Health and Suicide Prevention Inquiry

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Introduction

The Consumer Health Forum (CHF) welcomes the opportunity to make a submission to this Inquiry and thanks the members of the Select Committee on Mental Health and Suicide Prevention for the invitation.

CHF broadly supports the findings and recommendations of the Productivity Inquiry Report into Mental Health, the Victorian Royal Commission, the Report of the National Suicide Prevention Adviser, the National Mental Health Workforce Strategy and other recent strategic reviews. These findings and recommendations are largely consistent with each other and with findings made in previous reports over many years, including those of the National Mental Health Commission in 2014[1]. They confirm that consumers and carers experience a mental health system that is fragmented, difficult to understand and navigate, and is not serving mental health care consumers or the community optimally. This consistency also makes it clear that the failings of the mental health system are widely understood and recognised. Because these failings are complex and systemic, they will be difficult and costly to address but, with increasing mental illness in the community and a cost that has more than tripled over the last three decades[2], it is becoming more and more critical to fix the system.

This submission relates the lived experience of mental health consumers to:

- the findings of the recent reports and reviews, including those of the Productivity Commission and the Victorian Royal Commission
- strategies for encouraging emotional resilience building, improving mental health literacy across the community, reducing stigma, increasing consumer understanding of mental health services, and improving community engagement with services
- the use, safety and regulation of telehealth services.

Added to the recommendations made in the reports being considered in this Inquiry, CHF makes the following recommendations to better support consumers of mental health services.

- Establish an independent national mental health consumer and carer organisation.
- Integration of other systems, including primary health care and aged care to provide seamless, holistic care.
- Implement structures to monitor and independently report on progress and achievements.

[1] National Mental Health Commission, 2014: The National Review of Mental Health Programmes and Services. Sydney: NMHC Published by: National Mental Health Commission, Sydney
[2] Australian Institute of Health and Welfare, updated 29 January 2021: Mental Health Services in Australia, Web Report https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/report-contents/summary-of-mental-health-services-in-australia

Issues

CHF is the peak body representing consumers of health services in Australia. The highlighted mental health issues in this submission have been identified by seeking the views and experiences of CHF members and other mental health care consumers. Some of these views are included in quotes throughout this submission.

There is an increasing prevalence of mental ill health in the community, and rates of comorbidity are also rising. Most importantly, suicide rates remain unacceptably high. CHF agrees with the National Mental Health Commission's 2014 review that identified impediments to improvement, such as:

- concentration of resources in costly acute and crisis care
- fragmentation of services and poor coordination between them
- services designed with a focus on the needs of providers, rather than consumers and carers
- inequitable access to care especially for people in regional and remote areas and for disadvantaged groups are major impediments to reform.

> *Early on in the process, I was left to coordinate supports through trial and error.*
>
> *There is no coordination of all the services. There are so many separate groups and most people have no idea where to go to for help and often manage alone. It is a minefield to navigate.*

CHF would add that other factors impeding the pace of reform also include:

- overreliance on the biomedical model of mental health care, rather than a biopsychosocial model that would factor in people's social and care structures
- blurred lines of responsibility and accountability between stakeholders in the system from governance, funding and service delivery perspectives, including in responsibility between the Commonwealth and state and territory governments, as well as with social services and programs, that leaves some people to fall through the cracks and makes the system harder to navigate or coordinate
- a risk averse and/or rigid approach to implementation and failure to uncover and address problems as they arise, and that would make sure that consumers don't fall through the cracks
- a lack of focus on outcomes and value, particularly at an early stage from the perspective of using evaluation, data gathering (including patient reported outcomes and experience data) and reporting to drive service improvement and system reform.

Whole of Government implementation

Australians have a right to a universal mental health care system that integrates seamlessly with other parts of the system to give person-centred access to essential services in the right place, at the right time and the right way.

The division of responsibility for policy and services across the Commonwealth, states and territories continues to confound integration – and mental health care consumers.

Governments need to work together to set out short, medium and long term agendas for action. The simpler and clearer the visions and principles of the mental health system can be, the better it will help health consumers and the health sector understand what world class mental health care should look like and how to navigate its complexity as it reforms. The agendas need to be clear about the obligations placed on each Commonwealth department and each state and territory government. They need to give consumers confidence that they can get the care they need, when they need it, and they need assurances that the system is properly funded and sustainable. A Whole of Government policy and implementation roadmap that includes co-design, high visibility and accountability is likely to improve community trust and provide the assurances people need.

While not within the scope of this Committee, greater consideration must also be given to the social determinants of health, especially during and in the aftermath of the pandemic. There needs to be increased support for people who face social and economic disadvantage, including people from culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander communities, people receiving government payments as their main source of income, people with insecure housing, and sole parents. There is a strong association between poverty and poor mental health.

Funding models

Consumers with multimorbidity, who are the norm, are not well served by accessing mental health services in isolation. They need a mix of clinical, treatment focused interventions, together with clinical and non-clinical services to support their recovery and help avoid relapse.

As the inquiries and reviews being considered by this Inquiry have reported, the international evidence shows that national health systems with strong primary care infrastructures have

I have had PTSD since 1977, and had my first case of shingles, so had to go weekly to GP for vitamin B injections for 2.5 years and have been on an antidepressant for at least 30 years. It has been very expensive. Thousands of dollars. I didn't have a healthcare card or any form of compensation.

It would have been useful if I did not have to pay $700 of my own money to get an autism diagnosis!

healthier populations, fewer health related disparities, and lower overall costs for health care, than countries that focus on specialist and acute care.

To achieve this, mental health services need to be integrated across all health care services, and especially with primary health care services. Consumers need:

- comprehensive and multidisciplinary services, both within a service and across service settings, that are coordinated by a team of providers trained in consumer centred care
- patient centred health care homes that integrate primary health care services, self-management support and social prescribing
- early identification and intervention of mental health care needs, as a fundamental principle to reduce severity and maximise recovery
- social prescribing to maximise community support to improve consumers' overall health and wellbeing, especially for vulnerable people, including those experiencing long term mental health issues or social isolation.

Too many to mention!! Eye rolling, forgetting my name during treatment, making negative assumptions about my gender and ethnic background, speaking down at me, referring to me as Just The Mother, rushing into prescribed medication rather than willing to listen, using terms such as 'terrible ' and 'too hard basket' and most of all... telling me I can never expect to lead a fulfilled life. Terrible.

We sought public hospital support, were told they would come after 5 days they didn't assess, and my son attempted suicide. Team was very aggressive and combative.

They fobbed off my concerns. They rushed. They were uncomfortable.

Medicare funding purely of fees for service are not appropriate for this model of care. A modern and more flexible model is required to equip general practices to take responsibility for managing and coordinating care for patients with chronic conditions. CHF advocates the introduction of patient and family centred health care homes, featuring:

- voluntary enrolment/registration
- blended and bundled payments for general practices, so that they can configure teams of health care professionals to provide patient centred, multidisciplinary care, including primary mental health care delivery
- more active use of telehealth and other technology.

Medicare could also be strengthened by developing regional budgets, flexibly administered by Primary and Local Health Networks, that combine Commonwealth and state/territory funding.

Patient centred care

A lot of the time I felt like I had lost any sort of control in making decisions, the "goal posts" felt like they kept moving and sometimes it seemed like the "team" of professionals didn't know what each other were doing or trying to achieve. I lost confidence and trust.

When my partner was Form 1 I had no say in his treatment, the health nurses and doctors told our family to stop ringing and ask how he was.

I have a positive and respectful approach, so I'm treated with respect. I've been lucky, I guess.

CHF has long advocated for patient centred care across all health services and systems. Features of a patient centred care system include:

- mental health services that wrap around the person
- involvement of people with lived experience, together with their families and support people, so that they encounter a system that involves them in decisions, is easy to navigate, and provides continuity of care
- access in the right place at the right time
- being outcomes' focused
- being a publicly understood and known system
- responsiveness to whole of life needs.

I have many physical conditions that need treatments as well as my mental health. I always have to have a long appointment when I visit a GP. The GP does bulk bill, but you have to have the money in your account and pay upfront for the $100 or so consult, then you can get the gap back on your card. I'm constantly having to choose between whether to get see my doctor because of my physical problems or mental health problems. It's a constant juggling act and because of this and because of the costs of GP visits, neither my physical nor mental health is getting the care it needs. I find this extremely upsetting and stressful.

Some people are supportive, others not. Some people understand one area/issue, although often no or little knowledge/understanding in other areas. Often physical symptoms have been dismissed as mental. A huge mouth pain dismissed by many until a dentist referred me to an oral specialist - saw them and the next day a pre-mouth cancer cut out. I was told that if I'd gone public would've died waiting.

Mental health consumer/carer peak

A missing component in our national architecture, and in the reports from recent inquiries, is an independent, system-focused national mental health consumer and carer peak body. A national organisation of this kind would influence the future of health programs and services by including consumer and carer insights, aspirations for a better system, and lived experience.

Consumer insights and involvement in shaping national policy and programs applies not only to specialised mental health services, but also to the wider health and social services that are used by people with mental illness and their carers. Their voices must be included in established national, state and territory consumer peak bodies developing policy positions and strategies, and they should be supported by those organisations to build their capacity to contribute.

An important role of the mental health consumer and carer peak body will be to support consumers and carers to both have a voice in their own health, support and treatment decisions, and to take leadership roles where they can contribute to, and advocate for, policies, programs and systems to better support consumers and carers more broadly.

Regional reform

CHF strongly endorses the views expressed in earlier reports that the Primary Health Network (PHN) be used to harness the infrastructure to better target mental health resources to meet population needs in each region of Australia. Together with Local Health Networks (LHNs), they would be well placed to implement arrangements to prioritise primary mental healthcare and incorporate consumer and carer participation in decision making. More systemically, they

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In the public hospital system, the person I was caring for was told what to do by a different health professional each visit. This mostly involved a new medicine prescription for a medicine with strong side effects and very little discussion.

I have no support with coordination, I direct my own care

Early on in the process, I was left to coordinate supports through trial and error

Support is almost hidden, it is difficult to find support groups in remote and rural settings for both the carer and the person with the mental illness

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are well placed to work with to develop agreed regional mental health and suicide prevention plans and explore innovative ways of taking these forward, such as co-commissioning of services.

Monitoring and reporting outcomes

A “shared truth” of the experiences of mental health systems and services by consumers and carers is needed for effective reform.

Existing data collection processes should be coordinated into annual reports to Parliament. Reporting to Parliament attaches a higher level of significance, accountability and transparency than could not achieved through any other mechanism. The report should:

- take a Whole of Government perspective
- be accessible to, and meaningful for, consumers
- use data that is already collected, or could easily be collected
- be produced by an independent organisation.

Conclusion

CHF welcomes the opportunity to contribute to this Inquiry and supports reform of the mental health system by implementing the recommendations of the Productivity Commission report, as well as additional recommendations that focus on consumers as set out below.

- Establish an independent national mental health consumer and carer organisation.
- Integration of other systems, including primary health care and aged care to provide seamless, holistic care.
- Implement structures to monitor and independently report on progress and achievements.