

**Submission to
Royal Commission into Victoria's Mental Health System**



Anxiety Disorders Association of Victoria, Inc. (ADAVIC)

July 2019

About ADAVIC

ADAVIC provides “grass-roots” SUPPORT, INFORMATION and RESOURCES for the community relating to anxiety and depression, and issues such as panic attacks, phobias, obsessive compulsive disorder, hoarding, post-traumatic stress disorder, and self-esteem problems.

ADAVIC wants to achieve good outcomes, like keeping people empowered and connected. We take a preventative approach by providing high-quality assistance about strategies and treatment options, which can often be the difference between recovery and life-long systemic dependency. Our clients always have access to the latest empirically-based interventions through professionally-delivered educational events and information resources.

ADAVIC is a responsive and active grass-roots organisation. We deliver impartial and independent information to the community and provide a range of options to encourage people to find the help that works for them. Since ADAVIC is an entry-point service we can strongly influence outcomes by bridging the gap between self-help, social support, and professional treatments. We reduce barriers to help-seeking by providing a range of services and options that are practical, affordable, accessible, and non-prescriptive.

Our Team

ADAVIC is a small, self-funded, community-based organization which relies on a dedicated team of volunteers to deliver our services.

- Volunteers (50+)
- Staff (2 casual, 0.5 FTE)
- Committee of Management (10 members)

ADAVIC services

Features of our services:

- Accessible, inexpensive, and low-commitment reduces barriers to help-seeking
- No service catchment areas or restrictions
- Day and night services for better access

What we provide:

- PHONE SUPPORT, INFORMATION and REFERRAL service (3 days per week)
- FACEBOOK SUPPORT service (6 days per week including evenings)
- EMAIL SUPPORT service
- FREE RESOURCES such as our Information Packs and website
- WORKSHOPS & LECTURES conducted by qualified mental health professionals
- PROFESSIONAL DEVELOPMENT EVENTS to keep health professionals up-to-date
- SUPPORT GROUPS (weekly meetings)
- WEBSITE with frequently updated resources

In a typical year, ADAVIC ...

- responds to over **500** calls and **600** emails for support, information & referral
- responds to more than **7000** support requests on our Facebook page (with over **230,000** 'likes').
- runs **12** educational lectures, **2** workshops and **4** Professional Development Events (over **500** attendees per year)
- receives more than **200,000** visitors to our Website
- hosts weekly Support Group meetings with an average of **5** attendees per meeting (over **800** attendees per year)

Submission to the Royal Commission

ADAVIC appreciates the opportunity to provide input into this important and necessary Royal Commission into Victoria's Mental Health System. There are many aspects of the system that work well and can be built upon. However, there are also many opportunities for improvement, and some things that must be fixed.

We aim to share with you some of our learnings from the past 25 years with our experience as a small, self-funded association providing "grass roots" community support, information and resources for anxiety disorders, stress, and depression. This is informed by our own experiences as staff, volunteers, and students in the mental health sector, and from those who have shared their journey with us including the general public as active participants of our services or individuals and friends and family who have made contact with us. It includes the professionals and para-professionals who work in Victoria's Mental Health system, or who are impacted by the system, such as teachers, support staff.

We highlight the following issues for consideration:

- 'Support' is a service in its own right
- Make it easier for people to access the right help at the right time
- Recognise the broader life impact of mental health including safety-net of services.
- Utilise the strengths of the wider health sector and leverage its size for better impact
- Understand that an individual exists within a community (an ecological, systems approach)

In general, we ask the Commission to recognise the intrinsic value of group work and to provide stronger mechanisms and appropriate ongoing resourcing to support the functioning and sustainability of small non-government organisations like ADAVIC, who work with communities in a predominantly voluntary capacity to fill an essential gap between Commonwealth primary mental health and state-funded active services. Agencies like ADAVIC need better support to build capacity of volunteer staff to ensure our reach into local communities is maximised, links to relevant services, and aligns with broader government priorities.

Key recommendations:

- Recognise and appropriately resource and leverage the value of lived experience
- Aim for user-lead and consumer-driven service design, supported by the experiences of the health sector workforce
- Recognise the value of a peer workforce and fund opportunities to better embed effective peer support models within the sector
- Stipulate requirements for state-based (or national) shared tools and templates that enable small NGOs and agencies that rely on voluntary staff support.

‘Support’ is a service in its own right

We urge the Commission to recognise that community ‘support’ is a valuable and valid option for enhancing an individual’s wellbeing, and the community’s wellbeing. Community support is to be contrasted with ‘treatment’ or ‘intervention’ as we believe that community and peer support can provide intrinsic value without needing to be outcomes-based or solution-focused. Our experience at ADAVIC suggests that it can be adjunct to treatment, and also its own type of ‘healing’, and significantly contributes to helping people’s pathway to recovery. We view this concept as most easily understood through terms like; ‘emotional support’, ‘a listening ear’, ‘being there for someone’, ‘having time for someone’, and ‘being present’. We believe that community support as a service offering is under-valued and de-prioritised in state policies and programs and has limited funded services allocated to this purpose. There is often not the time or resources available to provide community or peer support. Many of the complaints we hear from the public about their experience of the sector relate to the lack of time by agencies, being rushed, not being given the opportunity to felt ‘heard’ or ‘understood’.

Humans are social beings. Wellbeing is related to having significant reliable and positive personal and social connections. Some mental health concerns may be caused by relational issues and challenges, or exacerbated by them, such as disconnection or disengagement with important others in one’s life. Alternatively, mental health concerns can cause and exacerbate relational issues with others, especially the stigma associated with it, either from others, or often, self-stigma and self-blame by individuals themselves.

Feeling heard, being validated, having someone acknowledge your story and hear your pain – these are real things that have weight for individuals experiencing mental health concerns. Some feedback from our participants highlights the value of support:

“Thank you from the bottom of my heart, it means so much to have you genuinely care and to have you take the time to offer support and advice. I truly appreciate every one of you and I am so glad I have found this organisation.”

“I instantly felt all the effort you went to researching resources for me literally hit my heart with warmth. There is not one solitary person that has ever helped like this; this what I desperately needed.”

Recommendation

- We propose that the Royal Commission recommend that the Victorian Government invests in appropriate funding for systems and structures which can embed support options and resources for the community, especially for peer-supported resources, and self-help options. This could be via traditional service agencies and modes of service delivery including generalist and specialist providers in health and mental health services, as well as alternative delivery modes to reach people where they are – at school, work, clubs or within their community at organisations like ADAVIC.

Make it easier for people to get the right help at the right time

At ADAVIC we have found that most people are willing to do something about their mental health situation, but don't know how, or don't have access to the resources, or don't have the mental or physical energy needed to 'lift themselves up'. For some people, their first awareness of having a problem is when it's 'right upon them', when it's too late for preventative maintenance or proactive measures. This puts people in position of dependency and vulnerability. For some people, their awareness of something being wrong is the first time they have interaction with the mental health system. As an organisation, we have heard often that the system fails when people need it most. The system needs to better support early intervention and helping friends and family to know how to respond when they notice something is 'not quite right' with someone they care about.

A well-designed system should be able to do the heavy lifting for people, rather than adding additional weights and barriers to their individual load. For example, the mental health system is complicated, even for those who work in it. There are multiple funding streams, program acronyms, primary and tertiary platforms, generalist and specialist agencies, a range of individual providers of different professions, multiple treatment options, symptoms and condition diagnoses, medication concerns, as well as Medicare and Private Health Insurance. The system is difficult to understand and navigate, and difficult to access the help which will match the need, in the right setting, at the right time.

At ADAVIC, we have found that although awareness of mental health and illness is better (such as via national efforts of beyondblue as well as established wellbeing programs and wellbeing coordinators in schools), mental health literacy is still very low. Individuals do not often understand the nuances of the system, let alone some of the basics such as symptoms or causes of mental health conditions, or therapy types, treatment options, alternatives to medication, or the difference between a counsellor, psychologist and psychiatrist. And nor should they need to - the mental health system needs to simplify the pathway for individuals and their families, and wherever possible make the involved parts work together – without minimising the sophistication needed for dealing with the challenging and complex issues of mental illness.

People are often forced to wait days, weeks or months to access professional help, after undertaking convoluted intake, assessment, and eligibility procedures. They often are required to 'tell their story' multiple times to different service providers even with the same service agency.

Some people need more help with mental ill-health than others and these needs should be prioritised. While some people's needs are less severe and non-urgent, these needs still should be addressed in a timely matter. A person should not have to wait until they are 'seriously unwell', nor should they need to have sufficient symptoms or a formal diagnosis ('eligibility') before they can enter or benefit from the Victorian mental health service system. This is based on a principle of equity and of prevention and early intervention.

Mental health symptoms impact people across the day and night, not just during business hours. This is because mental health symptoms have a wider impact than just the mind – they can impact the body, diet, sleep, relationships, work, study, housing, and so on.

Victoria's mental health service system should provide accessible services when it is needed, day or night. It should recognise the life impacts of mental ill-health and provide multiple options and resources which can address and support these needs. ADAVIC believe this should include dedicated supports for communities to self-manage their own health and wellbeing.

Recommendations

ADAVIC proposes that the Royal Commission recommend that the Victorian Government:

- Provide improved funding and structural supports that enable sustainable, safe and effective services to be available and accessible:
 - At night time and on weekends, beyond standard business hours
 - Wherever a person lives and regardless of what a person can afford
- Encourage investment in a service system that provides safe and effective opportunities for individuals to connect, engage, support, belong with other individuals and their community.
- Identify policy and funding supports which enable services and resources to be implementable by a wider range of ‘service providers’ – including professionals, para-professionals, and non-professionals, peers, and persons with a lived experience of mental ill-health. This includes identifying efficacious services and resources which can be most easily allow for ‘self-help’ by communities.

Implementation principles and suggestions

That the Royal Commission explore how to:

- Recognise the value of soft entry points for the mental health system, including gateway services that offer easy entry and access points. Soft entry points are important as they can help people understand the issues through scoping, options identification, sign-posting and ‘where-to-from-here’, assisting people to travel from general information to specialist advice or intervention. Identify the desired qualities, reach, remit, functions and outcomes of these services and fund them appropriately.
- Simplify access to the service system through service re-design that is user-led or informed by the experience of all major stakeholders in the system (participants and service workers). This should incorporate journey mapping, user experience mapping, system design thinking, pathway analysis, and would include all significant stakeholders such as the individual, family and friends, service providers and funders/policy-makers.
- Expand the accepted approach of delivering services from beyond the traditional service agencies, to a wider and broader selection of alternatives and innovations to reach people where they are – such as at school, work, clubs or within their community. Digital service offerings can bring positive disruption to the sector without minimising the value of face-to-face services, and can allow for instantaneous information, support or assistance in some cases, as well as enabling service delivery beyond typical business hours.
- Many mental health conditions have similar symptoms and negatively impact people across the same life domains and perhaps in the same way. Acknowledgement and funding for transdiagnostic services – those not limited to specific conditions - can provide support, information and care options for a range of shared factors which are common to the mental illnesses, or for people experiencing symptoms of multiple conditions (co-morbidity), as well as for sub-threshold or not-yet-diagnosed conditions.
- Better acknowledge that medical services (especially medication) are not always the most suitable forms of treatment, as well as recognising that “the Western Medical model” may not fit for all. We note that of the services we provide, the ones where individuals can connect and engage with others, seem to be our most meaningful for participants. Mental health challenges can be very isolating. Opportunities for connection with peers, non-

professionals, and professionals with lived experience helps to de-mystify and normalise mental health. As expressed by two of our peer support group participants:

“My need is a cure for anxiety. However, the social interaction and mutual support of the small group of diverse people as well as the professional approach of the facilitators left me feeling good about myself on every occasion.”

“Before going to this group, I felt alone with my anxiety and felt like I was the only one in the world with it. But since coming to this group I have found by talking to the right people and sharing ideas with people in my position there are ways of helping yourself.”

Leverage the strengths of the wider health sector for better impact

The mental health service system and associated systems are large, have many players, and can be convoluted, duplicative, and inefficient and difficult to navigate for people experiencing mental health concerns. There are a significant number of service providers, agencies, funding streams and resources within these systems that can benefit those who need mental health assistance.

For ADAVIC participants, these complexities can create barriers rather than enablers to gaining integrated mental health supports.

Recommendation

That the Royal Commission explore new integrated service models that make better use of the existing funding, structures and agencies within the mental health service system to leverage these strengths and opportunities.

Implementation principles and suggestions

That the Royal Commission explore how to better utilise the existing agencies, resources, service providers and good will within the sector wherever possible through:

- Mapping the service system to understand the gaps in services, large and small, and the areas of duplication and intersection, as well as the breadth of individual providers including health and mental health professional, para-professionals (teachers, others), and non-professionals. This will provide a shared picture and high-level visual of how the system operates and who operates in it, and how a person with specific needs may be supported in that system.
- Undertaking user journey mapping – as an individual who needs help or as a friend, family, carer, or as a service provider, to understand who does what, when, why and where.
- Supporting coordination of state-funded networking and inter-agency collaborative partnerships.
- Utilising weight in numbers, learnings and pool resources where possible, such as by:
 - Identifying an agreed set of shared and simplified tools and templates for use across agencies to allow for easy screening, assessment, formulation, record-keeping and referral to encourage better service coordination, integration, and to minimise duplication and the administrative burden on agencies
 - Identifying software platforms that could be licenced in bulk and utilised by agencies for many uses, such as for secure information sharing with consent, privacy and

- security being key concerns, or for staff and volunteer management, or for service bookings, event management, and service statistics collection and monitoring.
- Utilising big data for trend analysis, predictive analysis, and strategies utilised in other (non-health) sectors who have made advantageous use of information – what can be predicted about mental health, mental-ill health, consumer needs and resource allocation through data? From many perspectives it seems as though service provision is still very much operated via an old-fashioned manner, within older paradigms (sometimes due to state policy direction or funding restrictions) with limited progress, innovation or technical improvement in many aspects, despite its desire to be evidence-based, innovative, and a proponent of the scientific method.
 - Developing a shared workplan for the Sector for improving mental wellbeing for the community and uniting the diverse service providers. This could be a state-level plan with agreed principles, values, and identified KPI's that all service providers could check and monitor their progress against, and for which the Department can assess what's working, what could be adjusted, and how to ensure appropriate resourcing is committed and distributed to the mental health sector.

Holistic approaches that strengthen the individual in a community relationship

The experience of mental ill-health can be isolating and lonely, it can be an 'othering' experience. Beyond the symptoms themselves, the experience of accessing or receiving care can be scary, traumatising, or make people worse-off.

Many existing programs and services work to make this help-seeking journey easier and less painful, and to normalise, de-mystify and de-stigmatise mental health experiences and associated services and resources. As identified in the Royal Commission's Terms of Reference, a holistic approach to mental health services could address these issues.

Recommendations

ADAVIC proposes that the Royal Commission recommend that the Victorian Government:

- Recognise the value of lived experience and expand roles for lived experience in Victoria's mental health workforce
- Aim for user-led and consumer-driven service design
- Recognise the value of a peer workforce and fund opportunities to embed effective peer models within the service sector
- Identify and better utilise peer-led agencies and advocacy, such as ADAVIC that provide community-based advice.

Thank you for your consideration,

Anxiety Disorders Association of Victoria (ADAVIC)