



THE VICTORIAN MENTAL ILLNESS AWARENESS COUNCIL

Post-draft report submission to the Productivity
Commission on mental health

23rd January 2020

Executive summary

VMIAC's post draft report submission is in line with our vision of a world where all mental health consumers stand proud, live a life with choices honoured, rights upheld, and these principles are embedded in all aspects of society.

VMIAC is the peak Victorian organisation for people with a lived experience of mental health or emotional challenges. We're run by consumers, for consumers.

For decades, VMIAC has advocated for what matters to mental health consumers:

- We advocate for individual consumers with mental health and related services
- We provide support and information for people to advocate for ourselves
- We develop [resources](#) for consumers on high priority topics
- We are constantly talking and listening with diverse consumers to hear the issues and what people want
- We work closely with government and the sector, on committees, projects and policy reviews
- We run [campaigns](#), write submissions and develop policy positions about key issues
- We seek out [media coverage](#) to bring attention to our issues
- We celebrate consumer achievements
- We host [events and education](#) sessions for consumers

We know we're still a long way from achieving our vision of consumers' rights being respected and our choices being upheld—but we remain committed to achieving this vision.

Our work is premised on these beliefs:

- People's experiences are respected and valued
- People are experts in their own lives
- People have a right to self determination
- People have capacity to make genuine choices, free from coercion
- People should be safe, respected, valued and informed
- People's diversity is embraced

VMIAC's initial submission

Our CEO, Maggie Toko presented at the Productivity Commission hearing on Tuesday 19th November stating that:

'The principle is to build a mental health system that is truly person-led. I recognise that the draft report has the intention to place consumers at the centre of their care; there are references to psychosocial support and social determinants of health, but I feel these are without true understanding of what it means at the coalface, for the consumer on the ground.'

'Psychosocial support is not a quick fix. It is about a relationship building, relationship modelling, it is about identifying and developing skills you already have as an individual, as a partner, as a couple, as a family.'

'A system that has consumers at the forefront of care is a good system. As a society we should want to grow the foundations by having consumers participate in service design. '

'A peer-led workforce that is enabled to develop skills and qualifications and match other streams will be important to the future of those workers who have lived experience. A commitment by state and territories to acknowledge the lived experience workforce as a viable addition will generate a commitment to the value of co-design. '

'VMIAC is living proof that you can have lived experience and function on a high level. I acknowledge that this is not the case for all consumers, but it is not because of who they are but more to do with the social determinants that influence their available choices.'

VMIAC's response to the draft report

DRAFT RECOMMENDATION 11.4 – STRENGTHEN THE PEER WORKFORCE

In order to strengthen the lived experience workforce government must understand that lived experience work is a highly skilled and specialised discipline which requires ongoing training and supervision from experienced lived experience workers. Lived experience work goes beyond peer support workers and includes anyone who utilises their lived experience in a work role. Strengthening of this workforce will require major investment from government to ensure the lived experience workforce is appropriately cultivated to meet the needs of consumers, families and carers.

The professionalisation of the lived experience workforce, although welcomed, needs careful consideration. Firstly, there needs to be a clear distinction between a consumer lived experience worker; that is a person with personal lived experience of mental health issues or emotional distress, and a carer lived experience worker whose lived-experience is based on their role as a carer of someone with mental health issues or emotional distress. The two roles have very distinct needs and expectations and are appropriately and separately defined for this reason.

Secondly, career progression must be developed in order to retain lived experience workers so that they may be able to share their expertise and provide supervision to more junior lived experience workers as well as develop their own careers.

Thirdly, lived experience work is not clinical work. It is vital that other mental health professionals not 'muddy the waters' by providing supervision not appropriate to lived experience work. Lived experience work needs to be supervised by lived experience workers.

Lived experience work should never be seen as a 'steppingstone' to entering other mental health professions. Lived experience work is a respected profession in its own right and deserves the appropriate funding in order to grow.

VMIAC does not agree with the Productivity Commission's draft recommendation that 'peer worker qualifications ... be recognised as prior learning for health professional qualifications.' This clearly undermines the profession and is not a commitment to strengthening the lived experience workforce.

Finally, any future proposed guidelines regarding the lived experience workforce must be co-designed by consumers and lived experience workers.

https://www.cmhl.org.au/sites/default/files/resources-pdfs/CMHL-Intro-to-LEW-roles-v3-20190227.pdf?_ga=2.112501312.574534772.1574729203-684566478.1570171400

DRAFT RECOMMENDATION 12.2 –GUARANTEE CONTINUITY OF PSYCHOSOCIAL SUPPORTS

DRAFT RECOMMENDATION 12.3 –NDIS SUPPORT FOR PEOPLE WITH PSYCHOCOCIAL DISABILITY

Nothing about us without us

VMIAC stands firm that it is unacceptable for the National Disability Insurance Scheme to replicate the broken system that historically and currently surrounds the scheme. Nor is it acceptable to refurbish systemic problems within the scheme without meaningful and long-term consumer consultation and codesign at every level.

VMIAC stands firm that any analyses or proposed changes, such as the discussion around NDIS support for people with psychosocial disability, need to be firmly situated within the experiential, theoretical and systemic experience of consumers. It is only with meaningful consumer expertise knowledge and engagement, at all levels- that the scheme can best fulfil its intended purposes for psychosocial- based participation.

Recommendation 12.2 outlines the guarantee of continuity of psychosocial supports. VMIAC has gained expertise in the vast array of issues underpinning engagement and disengagement with the NDIS and broader mental health system(s). This has been achieved through ongoing, direct and detailed consumer engagement. The continuity of psychosocial supports requires a much more nuanced analysis and response than proposed. VMIAC identifies that the issues are largely due to systemic lack of consumer self-determination and input into the scheme, despite the rhetoric and premise of choice and control. Therefore, VMIAC calls for meaningful input to inform knowledge of issues including, but not limited to, inappropriate supports, a broken landscape of unclear pathways, no clear map or clear meta-structure, and lack of person-centred care, punctuated with adversarial red tape.

Recommendation 12.3 NDIS support for people with psychosocial disability- outlines short- and medium-term solutions to improving the scheme.

VMIAC stands firm that it is unacceptable for the NDIS to replicate the broken system that historically and currently surrounds the scheme. Nor is it acceptable to refurbish systemic problems within the scheme without meaningful and long-term consumer consultation and codesign at every level.

VMIAC calls for an unprecedented, all-encompassing inclusion of experiential, theoretical and systemic **consumer** experiences and perspectives. This will assist in successfully shaping the future of the NDIS. Include plan architecture and funding, participant experience, appropriate access criteria and interpretation of legislation. This will flow on to influence broader mental health services and peripheral landscape. We remind the commission and its counterparts that in the psychosocial space, the NDIS is just one avenue offered to a minority of people experiencing psychosocial disability and therefore must not operate in a silo from the broader mental health support system.

We ask that future directions of governance, infrastructure, funding considerations and consumer engagement is shaped by what consumers themselves articulate as their needs. The growth of consumer directives must be taken on within the evolving NDIS.

Consumers are best positioned to define what works, what good services and interfaces look like, and we urge the NDIS to embrace our expertise. To do so will reduce systemic errors, stop people losing functional capacity as a result of bad service delivery and improve economic viability and KPIs for the scheme.

The short, medium and long-term recommendations need consumer input beyond what has been cited in the productivity report.

The NDIA needs to urgently elevate its approach for change and evolution so it is a large-scale refurbishment. This will assist in successfully shaping the future of the NDIS. Key areas include plan architecture and funding, participant experience, appropriate access criteria and interpretation of legislation. The current and ongoing crisis of consumer engagement with the NDIS requires consumer-focused codesign with consumer experts and organisations. As explored in the report, current practice results in exclusionary interfaces, inconsistent, short-term, ever-changing points of contact, traumatising delays that result in decreased functional capacity; unskilled, unregulated interpretations of legislation and evidence that results in exclusion to the scheme or inappropriate plans, and dismissive, inadequate information sharing and support mapping. The role of Local Area Coordinators (LACs) and planners needs to be reinvented so they partake in the process of engagement beyond the planning meeting and can do so in a person-centred, empathic, appropriate manner. The devastating experiences and outcomes for consumers in the NDIA space is well mapped and documented by VMIAC.

DRAFT RECOMMENDATION 16.6 – LEGAL REPRESENTATION AT MENTAL HEALTH TRIBUNALS

DRAFT RECOMMENDATION 16.7 – NON-LEGAL INDIVIDUAL ADVOCACY SERVICES

Our members view access to advocacy as being paramount to the protection of inpatients' rights, particularly for those under a compulsory treatment order. Here in Victoria The Mental Health Act makes it lawful to restrict many of our rights. Some of the most common restrictions include:

- Detention in hospital
- Compulsory treatment, including both medication and electroconvulsive therapy (ECT)
- Seclusion (solitary confinement)
- Physical restraint (being held down by staff)
- Mechanical restraint (being tied down with straps)

When faced with such restrictions it is vital that consumers receive appropriate advocacy, either through legal representation or through an independent advocate who can provide supported decision-making that is free and confidential.

VMIAC strongly supports government investment in independent advocacy as an **opt out** rather than opt in service so that all consumers on compulsory treatment orders can have their voices heard.

VMIAC firmly believes that legal representation and non-legal individual advocacy services should be a fundamental right to mental health consumers and should not be dependent on the availability of funding or grants.

<https://www.imha.vic.gov.au/sites/imha.vla.vic.gov.au/files/imha-rmit-evaluation-of-the-independent-mental-health-advocacy-service-03-2019.pdf>

DRAFT RECOMMENDATION 22.3 – ENHANCING CONSUMER AND CARER PARTICIPATION

In principle VMIAC agrees to the enhancement of consumer and carer participation. **VMIAC does however, ask for a stronger recommendation regarding the involvement of consumer voice in mental health care system planning, design, monitoring and evaluation.** These activities should be undertaken utilising the principle of co-production as identified in Roper, Grey and Cadogan's (2018) open access resource 'Co-production; Putting principles into practice in mental health contexts.'

https://recoverylibrary.unimelb.edu.au/_data/assets/pdf_file/0010/2659969/Coproduction_putting-principles-into-practice.pdf

DRAFT RECOMMENDATION 23.3 – STRUCTURAL REFORM IS NECESSARY

In order for the Productivity Commission to understand what a consumer-led vision of mental health looks like, VMIAC has created a collective vision of consumers called The Declaration <https://www.vmiac.org.au/declaration/>. This declaration was created by people from all around Victoria with lived experience of emotional distress, trauma, neurodiversity and mental health challenges. It was first launched on 1 November 2019 and presented to Minister Martin Foley the Victorian Minister for Mental Health. It has also been referenced by the Royal Commission into Victoria's mental health system's interim report.

DRAFT RECOMMENDATION 20.1 – NATIONAL STIGMA REDUCTION STRATEGY

In order to combat stigma, we need to acknowledge that we have very diverse ways of understanding the experiences that are often called 'mental illness'. **Less than 20% of people thought that 'mental illness' was a helpful or accurate description** (surveyed by VMIAC as part of our Declaration project). The language that most collectively describes our experience is this:

'We are people with lived experience of emotional distress, trauma, mental health challenges and neurodiversity.'

https://www.vmiac.org.au/wp-content/uploads/The-VMIAC-Declaration_01-Nov-2019.pdf

When planning for a stigma reduction campaign consideration needs to be given to alternatives to the normal approach to this. Evidence is clear that campaigns that encourage people to seek help or position that mental illness is just like any other illness actually increase discrimination and the wish for social distance.

<https://www.madinamerica.com/2018/07/anti-stigma-campaigns-enable-inequality-sociologists-argue/>

<https://www.theguardian.com/healthcare-network/2013/apr/03/mental-health-anti-stigma-campaign>

DRAFT RECOMMENDATION 15.1 – HOUSING SECURITY FOR PEOPLE WITH MENTAL ILLNESS

DRAFT RECOMMENDATION 15.2 – SUPPORT PEOPLE TO FIND AND MAINTAIN HOUSING

Housing and real, supportive, social security were imperative dreams for many. We were saddened by the current state of society, when some people said their dream was 'to be able to afford food'. In a great society, we want connection with others, human rights and equity, respect and for society to stop pathologizing our beliefs, thoughts and emotions.

Mental health systems - Our dream was that a wonderful mental health system would be shaped by compassion, love and the social determinants of health. It would be trauma informed and holistic. And it would address climate change and be accessible.

DRAFT RECOMMENDATION 5.8 – INCREASE CONSUMER CHOICE WITH REFERRALS

Mental health workers - The two disciplines that were most often in people's dreams were peer workers and therapists. We note that these are two of the least funded roles in the mental health sector. The two qualities that we most often dreamed about were listeners and compassion.

Places and services - The places people most spoke about were peer-run services, and this included many variants: peer-run respites, recovery houses, crisis centres, peer support groups, recovery colleges and retreats. Many people dreamed about the importance of nature in an ideal healing space: gardens, trees, lawns, flowerbeds. Many also dreamed about light and windows.

DRAFT RECOMMENDATION 5.5 – ENCOURAGE MORE GROUP PSYCHOLOGICAL THERAPY

Supports - Groups, classes and therapy were the supports that were most often dreamed about. Victoria used to have a large community support system that provided many groups and classes, but these have largely disappeared since the advent of the NDIS. People wanted support groups, creative groups, therapy groups, peer support groups, nature activity groups, social groups, classes about life skills and recovery, and many more. Not everyone dreamed of groups. Some people explicitly said that their dreams would be for individual support because groups can be difficult. Therapy is also an impossible option for most of us, yet it is dearly wanted.

DRAFT RECOMMENDATION 5.4 – MBS-REBATED PSYCHOLOGICAL THERAPY

People dreamed about many different types of therapy, including trauma therapy, art therapy, music therapy, equine therapy, narrative and group therapy. Therapy is practically non-existent in the current public mental health system, Medicare does not support enough sessions for any kind of in-depth work, and so therapy is simply not accessible for most of us—yet. Music and art were commonly spoken about as powerful supports, as was taking political action. People spoke about being consumer activists, Black Pride, the #MeToo movement and speaking out about child abuse and family violence. Conversations and listening were also strong themes. Many spoke about the deep need to be heard by another person, to talk over what was happening to them. Some people said that the best people were not people at all: but animals.

DRAFT RECOMMENDATION 5.9 – ENSURE ACCESS TO THE RIGHT LEVEL OF CARE

Accessibility - Walk-in access was a dominant theme. We want to be able to just walk into a service and receive support. We want streamlined access, with no or much fewer forms and bureaucracy. We want help when we ask for it. If we say we are in a crisis, we want to be believed, not assessed and sent away.

Not only would outcomes be more cost effective, but people said they would leave services feeling happier. They would feel accepted and cared for. They would have employment, justice and human rights. They would feel connected to other people. **Surely, such outcomes are beyond any price tag and should be the benchmark of a productive and worthwhile mental health system that actually enhances the lives of all Australians.**

INFORMATION REQUEST 23.1 – ARCHITECTURE OF THE FUTURE MENTAL HEALTH SYSTEM

How could the Rebuild Model be improved on?

VMIAC supports the Productivity Commission's preferred approach of a Rebuild model, under which State and Territory Governments establish 'Regional Commissioning Authorities' using the principles of co-production. VMIAC strongly recommends the inclusion of the National Consumer Peak Alliance as part of this process.

The biennial VMIAC conference 2019 saw the formation of a National Peak Consumer Alliance, bringing together six consumer peak bodies from Victoria, New South Wales, Tasmania, South Australia, the ACT and Western Australia to have more influence on national policy. This brief statement was originally broadcast live via Periscope and, as at 29/11/19, had been viewed more than 1,200 times.

<https://www.youtube.com/watch?v=peAtjHgFxVo>

VMIAC sincerely hopes that the voices of consumers are at the forefront of the Productivity Commission's final draft. Anything less would be a waste of time, resources and a risk to the mental health of all Australians for generations to come.