



**VMIAC report on Barriers to Engagement with the  
Disability Royal Commission  
June 2023**

**Acknowledgement:** VMIAC proudly acknowledge Aboriginal people as Australia's First Peoples and the Traditional Owners and custodians of the land and water on which we live and work. We acknowledge Victoria's Aboriginal communities and culture and pay respect to Aboriginal Elders past and present.

*We recognise that sovereignty was never ceded and acknowledge the significant and negative consequences of colonisation and dispossession on Aboriginal communities.*

*Despite the far-reaching and long-lasting impacts of colonisation on Aboriginal communities, Aboriginal people remain resilient and continue to retain a strong connection to culture. We acknowledge the strong connection of Aboriginal people and communities to Country, culture and community, and the centrality of this to positive mental health and wellbeing.*

## Barriers to Engagement with the Disability Royal Commission for People with Psychosocial Disability

This document was produced by the Victorian Mental Illness Awareness Council (VMIAC) the peak body for Victorian mental health consumers. VMIAC is run by consumers, for consumers.

By 'mental health consumers' VMIAC means people with lived experience of mental health challenges, trauma, or emotional distress, and who have accessed mental health or related services to support their wellbeing. Our vision is a world where all consumers stand proud, live a life with their choices honoured, have their rights upheld, and where these principles are embedded in all aspects of society.

VMIAC supports consumers State-wide across metro, rural and regional communities. We provide individual and systemic advocacy to consumers with psychosocial disabilities, using a rights-based approach.

VMIAC's work includes leading:

- Systemic policy advocacy and campaigning
- consumer-led self-advocacy support
- consumer-led NDIS-related information and support
- training and consumer capacity development
- a Lived and Living Experience Workforce program
- operations of the Victoria-wide consumer register
- member and community engagement events and opportunities
- member and community outreach and information
- consumer-led research project support
- consumer service-experience secondary consultations
- consumer research secondary consultations

In this document, we discuss barriers people with psychosocial disability have experienced engaging with the Disability Royal Commission (DRC). These barriers were identified through staff observation of consumers experiences during their engagement with VMIAC for support with their DRC submissions, and a survey undertaken with those same consumers during and after the Disability Royal Commission submission period. We use the terms "people with psychosocial disability" and "consumers" interchangeably throughout this document.

## VMIAC Disability Royal Commission Survey

VMIAC's Disability Royal Commission (DRC) survey collected feedback on the experience of mental health consumers we assisted through our DRC support program as they engaged with the Disability Royal Commission. The survey focused on identifying barriers people faced making submissions. All respondents to this survey provided consent for VMIAC to use their feedback in this report.

The survey contained the following 13 questions (which were optional):

1. Do you consent to VMIAC using direct quotes from your responses for the purpose of a feedback piece to the DRC as described above?
2. How did you first hear about the Disability Royal Commission (DRC)?
3. Do you have any feedback about the way the DRC was advertised?
4. Did you receive any information, assistance, advice or other support from a VMIAC staff member to plan, prepare or submit to the DRC?

5. Did you access any other information, assistance, advice or support from an organisation other than VMIAC? If so, what was the organisation?
6. Did you make a submission to the DRC on or before the deadline of 31 December 2022?
7. If you selected 'no', were you planning or hoping to make a submission to the DRC before the deadline?
8. If you were planning to make a submission by the deadline but weren't able, what prevented you from doing this?
9. What did you find most difficult about planning, preparing, or submitting to the DRC?
10. What did you find worked best about planning, preparing or submitting to the DRC?
11. Were there any barriers that made it difficult for you to plan, prepare or submit to the DRC that you have not mentioned above?
12. Do you have any feedback about the questions asked on the DRC 'Individual Submission' template?
13. Do you have any feedback about any other aspects of the DRC not mentioned above?

## Service scope during COVID-19

The COVID-19 pandemic presented engagement challenges for VMIAC's Disability Royal Commission Support team. In 2021, team plans to conduct a series of face-to-face consultations were disrupted by COVID restrictions preventing travel to regional and rural areas from our Melbourne office.

Following the lifting of travel restrictions, issues faced by regional people with disabilities remained an ongoing concern. Many people also felt there was a lack of clear guidance from government and health authorities, particularly for immunocompromised and disabled people who were expected to adjust to a "new normal". To minimise the risk of harm to program participants, VMIAC chose to continue providing remote phone and web-based support.

Most people the DRC program supported were VMIAC members and were referred from other VMIAC programs such as the Appeals, NDIS and the consumer Advocacy service funded through the National Disability Advocacy Program (NDAP). We note support to participate in the Disability Royal Commission was also made available through mainstream services offering counselling and submission assistance. However, our service was taken up primarily by those who specifically sought a mental health Lived Experience run service.

## Key themes

VMIAC's DRC Support team identified the following themes across our work with people with psychosocial disability:

### 1) Limited targeted promotion and public awareness of the Disability Royal Commission

During the Disability Royal Commission submission period, VMIAC's DRC support team observed limited public awareness and promotion of the DRC within Victorian communities of people with psychosocial disability across metropolitan, regional and rural areas of Victoria.

Survey respondents discussed how the Disability Royal Commission was advertised:

*"Given that many people on disability support did not know about it, or how they could get support completing it, I believe there is still work to be done in how accessible and widely the information was shared."*

*“I didn’t see any advertisements for DRC, I just found out via VMIAC, so potentially advertising could have been better.”*

*“I was not aware there was a DRC until I was referred to it and it has only been the last 6-months I haven’t seen an office for it.”*

*“If it hadn’t been for VMIAC I would not have known about it.”*

## 2) Difficulty using or accessing technology

VMIAC’s previous experience in online engagement throughout the Royal Commission into Victoria’s Mental Health System between 2020-2021 allowed the DRC support team to transition to online engagement with relative ease.

However, many people living with psychosocial disabilities experience difficulties using or accessing technology. Therefore, while the team held online Disability Royal Commission community information sessions, these were not always accessible to people needing them.

In response, VMIAC’s DRC team supported numerous consumers facing technology related barriers – including those:

- who were unable to use the internet to obtain or complete forms required to make a submission.
- unable to engage with the online submission portal, download documents, use email, or attend virtual meetings.
- were only contactable by phone or post and had unreliable or limited email and internet access (e.g., access to an email account at a local library which was some distance from their home).
- who experienced technical issues with their home computer preventing access to their written submission for several months, leading to delays and lengthening the time VMIAC’s DRC team needed to support them.
- older consumers, and consumers living in rural and regional parts of Victoria, who lacked confidence using technology, making them more reliant on VMIAC’s phone-based support and transcribing service.
- who experienced impacts of psychosocial disability that deterred them from using technology to make their submission. For example, some consumers found it difficult to engage with audio-visual technologies due to heightened sensory experiences.

## 3) Lack of flexibility with Private Sessions

During a consultation between VMIAC participants and the DRC Community Engagement team on 17 June 2022, participants gave feedback about Private Sessions. These Sessions<sup>1</sup> were held by the DRC and allowed people the opportunity to share their experiences of violence, abuse, neglect, and/or exploitation one-on-one with a commissioner. Registrations for these Sessions closed on 30 June 2022.

Consumers said the 60-minute allocated timeframe was restrictive for the following reasons:

- it was difficult to “prioritise” time when they had multiple issues.
- the process was hard for those who required more time, but who didn’t want to split their time across multiple sessions.

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<sup>1</sup> <https://disability.royalcommission.gov.au/share-your-story/private-sessions>

- it required great effort for some consumers to set time aside and show up for one session.
- psychosocial disability and trauma made it difficult to use a computer for some consumers.

Support provided by VMIAC's DRC team members frequently occurred across multiple sessions lasting anywhere between 15 minutes and 150 minutes. Flexibility was allowed for session duration and overall length of engagement with the program to accommodate individual consumer needs. Some consumers engaged consistently - others had breaks in contact over the course of 12 months. Many submissions explored multiple service areas or settings and were not limited to just one event or period. Consumers typically experienced violence, abuse, neglect and exploitation across their lifetimes, so needed the space to address and give equal importance to multiple occurrences that impacted them.

#### 4) Lack of flexibility around submission deadlines/late submissions

Limited flexibility around the submission deadline, including provision of extensions, resulted in difficulty for some consumers to meet deadlines. These difficulties were exacerbated by mental health, or because of traumatic material.

#### 5) The impact of mental health, trauma

Living with psychosocial disabilities created unique barriers for some people engaging with the DRC. This included impacts on mood, attention, communication, episodes of poor cognitive functioning and need for/or neglect of self-care. Some consumers writing submissions experienced episodes of "acute" or heightened distress or illness, requiring them to discontinue or pause work on them to prioritise recovery. For those experiencing complex trauma, the retelling process was inherently difficult and retraumatising.

Feelings of hurt, shame, overwhelm and exhaustion arising through revisiting and reliving traumatic experiences had a lasting impact on the mental and physical health for some people, even long after the submission was completed. Particularly for those with inadequate supports (community, mainstream and informal). A proportion of consumers engaged with VMIAC chose not to continue with their submission for these reasons, either withdrawing contact or terminating their engagement with the VMIAC DRC team. One survey respondent said:

*"I have severe anxiety, and this kept preventing me from submitting it because I felt my story was not bad enough to submit and procrastination is a problem I have. I wasn't sure how to submit."* –

#### 6) The impact of other health conditions

Many consumers live with coexisting health conditions, disabilities, or chronic illnesses, which at different times take priority in their lives and have considerable impact. Forty-seven percent of Australians live with one or more chronic conditions, with 20% of the overall population experiencing mental health and behavioural challenges <sup>2</sup>. Despite this, there is limited mainstream literature and information available about the intersection of psychosocial disability and chronic illness. DRC engagement, public hearing themes and publications also reflected a lack of knowledge of these issues. This risked people feeling excluded from the definition of "disabled", and as though neither experience was "important" or "commonplace" enough to address in a submission.

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<sup>2</sup> Australian Bureau of Statistics (ABS) (2018). Chronic conditions. Available at: <https://www.abs.gov.au/statistics/health/health-conditions-and-risks/chronic-conditions/latest-release>

Consumers the VMIAC DRC team supported frequently rescheduled their sessions. In some cases, prolonging the length of support the DRC team provided. The reasons for rescheduling included the impact of chronic and acute illness, overwhelm, physical fatigue, competing health priorities and commitments. One consumer noted the impact of chemical restraint with a prescribed psychiatric medication – thereby limiting their ability to work on a submission.

Future inquiries need to accommodate the health needs of people with psychosocial disability so that submission processes are accommodating and accessible to them. This should involve a clear opening and closing date for accepting submissions that is widely advertised, as well as clear opportunities for people with psychosocial disability to request extensions as required. People with psychosocial disability should also have the opportunity to meet with an advocate or other kind of support person to assist them throughout the process of sharing their story with the inquiry, and applying for an extension if required.

## 7) Language and self-identity

Throughout the DRC submission period, many consumers approached VMIAC reception seeking support to share their stories of violence, abuse, neglect or exploitation within the mental health system. However, many callers were unfamiliar with the Disability Royal Commission, and when informed they could submit to it some consumers did not identify as disabled so didn't pursue making one. The concept of "psychosocial disability" is unfamiliar to many consumers. Historically, experiences of mental illness have been excluded from conversations about disability and assigned to a separate less visible category of "impairment". This can result in them being viewed as less deserving of support or recognition, alongside more "visible" disabilities.

This led to some consumers believing their experiences were not "bad" or "extreme" enough to warrant making a submission. Others were dissuaded by the terms of reference, not understanding completely what each of the terms meant, or otherwise believing their experiences did not fit neatly into any one category. Similarly, some consumers found it difficult to categorise their experiences, to discover after reflection they had experiences in all four categories.

## 8) Distrust of government systems and inquiries

VMIAC staff identified common fears and hopes among consumers about making submissions to the DRC. These included:

- making a submission wouldn't achieve anything or prevent negative experiences from happening again.
- sharing their story might retraumatise them.
- the risks of revisiting their experiences were too great to pursue a submission.
- fear of retribution and legal action by services for sharing their experiences (particularly for those in rural and regional areas).

Perceived hopes of making a submission included:

- being heard, listened to, and validated.
- feelings of resolution and achievement.
- making services answerable and accountable.

Many people with psychosocial disability experience negative and traumatic experiences of the legal and justice systems and/or have witnessed harm and human rights violations within the legal as well as mental health systems. This can include experiences of invalidation, being judged, or incarcerated when seeking support, experiencing distress, as well as unsatisfactory experiences of

complaints processes such as the Mental Health Complaints Commission and the NDIS Quality and Safeguards Commission. Some consumers also expressed fears of further harm, trauma, or retribution if they disclosed their experiences at the Royal Commission or deliberately sought to censor their experiences or retract the submission.

Furthermore, systematic minimising, pathologising, and demonising of consumers by service providers, within legislation and society can create fear and mistrust of government processes, staff, lawyers, and bureaucrats. Some people with psychosocial disability experience professionals with legal, justice and bureaucratic backgrounds as intimidating, unapproachable, difficult to relate to, and therefore trust.

People with disability need to see others who face similar challenges represented in government and justice systems. The DRC peer-provided support service was valuable in mediating some consumer anxieties and apprehension they had making a submission. The increased trust between consumers and staff in designated lived experience roles reflects literature on trauma informed service provision<sup>3</sup>.

When consumers were asked what worked best about the DRC submission process, one survey respondent said: *"[the] consistent support of TJ [VMIAC DRC advocate] to help me make a submission. I would not have done [it] [without] them."*

*"Talking with Romy [VMIAC DRC advocate] worked best."*

Another respondent wrote: *"It was the support I was given by the DRC in preparation for my submission that was the best thing and very validating. I had a 40min discussion with someone employed by DRC to talk about my issues to determine whether I met the criteria. I really valued this discussion. I was also offered pre-briefing support by another person linked to DRC."*

## 9) Negative prior experiences of engaging with the Mental Health and other Royal Commissions

Consumers' prior experiences and perceptions of Royal Commissions affected their engagement with the DRC. Some consumers shared having made submissions to past Royal Commissions, including the Royal Commission into Victoria's Mental Health System, Royal Commission into Aged Care Quality and Safety, and the Royal Commission into Institutional Responses to Child Sexual Abuse.

Those who engaged with these Royal Commissions expressed feeling dissatisfied and discontent with the process and outcomes. This included feeling like Royal Commissions have not improved safeguards or resulted in better protections for the affected communities.

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<sup>3</sup> Sophie Isobel et al, 'What would a trauma-informed mental health service look like? Perspectives of people who access services' (2021) 30 International Journal of Mental Health Nursing 495, p 498 - 501