Lived experience principle

1. What do **the Act** and relevant guidance say?

The lived experience of a person with mental illness or psychological distress - and that of their carers, families and supporters - is to be recognised and valued as experience that makes them valuable leaders and active partners in the mental health and wellbeing service system (s 21).

The lived experience principle reflects the Act's intention that people with lived experience play a crucial role in the design and implementation of improvement and innovation in the mental health and wellbeing system (Explanatory Memorandum, Mental Health and Wellbeing Bill 2022 (Vic), p 21).

People with mental illness or psychological distress, and their carers, families, supporters and kin are the experts in their own experiences and how they would like to be supported. This principle outlines how services can recognise and value lived and living experiences and ensure that it informs and drives system improvement and change. This includes those currently accessing, or supporting someone who is accessing, mental health and wellbeing services, as well as recognising and valuing the role of the lived and living experience workforce.

This principle also aligns strongly with Standard 2 of the National Safety and Quality Health Service (NSQHS) Standards (Australian Commission on Quality and Safety in Health Care, 2021) - Partnering with Consumers, which focuses on:

- consumers as partners in planning, design, delivery, measurement and evaluation of systems and services
- patients as partners in their own care, to the extent that they choose.

Just as the partnering with consumer standards underpins the rest of the NSQHS Standards, the lived experience principle underpins the rest of the mental health and wellbeing principles.

2. How do **human rights** relate to this principle?

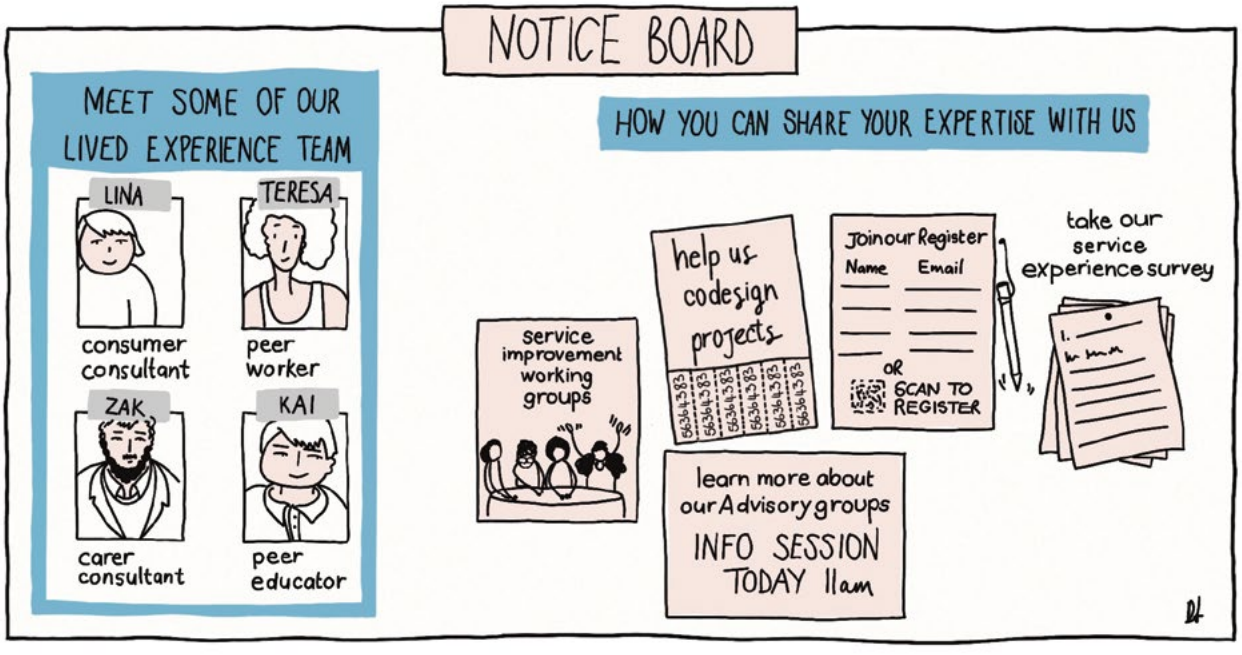
Central to the lived experience principle is the right to equality. Section 8 of the Charter states that 'all Victorians have the right to be recognised as a person, to enjoy their rights without discrimination, to be treated equally under the law and protected from discrimination'.

Due to its focus on recognising the leadership and active partnership role of consumers, carers, families and supporters, the lived experience principle underpins all other mental health and wellbeing principles and relates to all aspects of the decision making principles.

3. How might a **consumer** experience this principle?

When my lived and living experience is recognised and valued:

- I am seen as the expert in my own life, and my voice, views, and preferences are central to decisions about my treatment, care, and recovery.
- My lived experience is a strength. I am supported to express what matters to me, and it is taken seriously - even when it challenges standard clinical thinking.
- I have access to information and support, including peer support workers, consumer consultants, and carer consultants that help me make informed decisions.
- I can give feedback or make a complaint safely, and I trust that it will be respected and used to create meaningful change.
- I feel confident that my experience of the mental health system is welcomed and used to improve services for others.
- I am offered opportunities to contribute to service improvement in ways that are safe, inclusive, and empowering for me.
- I see people with lived experience in peer support and leadership roles within the service, and I feel represented and understood.
- I can identify and connect with lived experience workers who share similar cultural, community, or personal experiences to mine.



4. How might **carers, families and supporters** experience this principle?

When my lived and living experience is recognised and valued:

- My experience as a carer is listened to and valued. Services recognise that my insights can help shape better care and support.
- Services respect what I've learned from supporting someone with mental health needs and include me when planning care, in ways that align with the preferences of the person I care for.
- I see family members, carers and kin with lived experience represented in leadership and other visible roles within the service, and I know that family/carer perspectives help shape service policies and practices.
- I can give feedback about the service safely. I know it will be taken seriously and can help make things better for others.
- I can get support from people who've also been carers. This helps me look after my own wellbeing, feel less alone, and understand my rights as a carer.
- I am offered opportunities to contribute to service improvement in ways that are safe, inclusive, and empowering for me.

5. How can **services** put this principle into practice?

The lived experience principle has a particular focus on embedding lived and living experience leadership and partnership into services. Section 5 of Part One of this guidance and associated implementation resources include advice about leadership actions that will put this principle into practice. These actions must always be led by or codeveloped with lived and living experience. For example:

- Understanding the diversity of consumers, families and carers who use your service and ensure they are represented in lived experience engagement opportunities.
- Ensuring people with diverse lived and living experiences are involved in system change (for example, governance, design, training, measurement or evaluation) activities, and service delivery.
- Developing the lived and living experience workforce, including creating clear leadership structures, career pathways, and ensuring discipline-specific training, reflective practice and supervision.

This section outlines actions to put the lived experience principle into practice, as well as good practice suggestions.

Explore the key topics covered in this section:

- Recognise and value that people are the experts in their own lives
- Promote and learn from complaints and feedback
- Support the role of lived and living experience in systemic activities
- Support and value the lived and living experience workforce

Recognise and value that people are the experts in their own lives

Requirements include:

- Ask people what they need and want, support them to understand their rights including by providing appropriate supports (for example, interpreters, disability supports, involvement of supporters, IMHA advocacy) and to make decisions. See dignity and autonomy and supported decision making principles.
- Work in trauma-informed ways with consumers, carers, families, supporters and kin.
- Show cultural humility and respect for people's diverse identities and experiences. See cultural safety, gender safety and diversity principles.
- Involve carers, families, supporters and kin. See family and carers principle for detail.
- When speaking with consumers, carers, families, supporters and kin, and when considering the use of compulsory assessment or treatment or restrictive interventions, acknowledge that compulsory assessment and treatment and restrictive interventions significantly limit human rights and may cause harm including serious distress, and disruption to relationships, living arrangements, education and employment (s 80), and that restrictive interventions have no inherent therapeutic benefit (s 81).

Good practices include:

- Validate people's experiences by using and reflecting their language. For example, describe experiences as trauma, distress, crisis, or Madness - as preferred by the person rather than using solely clinical terms or jargon (University of Melbourne 2025, p 16).

Promote and learn from complaints and feedback

- Encourage consumers, carers, families, supporters and kin to give feedback and make complaints, and support them to do so, if needed.
- Ensure approaches to receiving and responding to complaints are culturally safe and trauma informed. For example, explain choices and protections, such as choice to make a complaint to either the service or the Commission, to involve support people, to ask for support from First Nations workforce within services or a First Nations IMHA advocate, to make anonymous complaints, that people must not be treated differently for making a complaint.
- Embed lived and living experience in analysing feedback and complaints to identify themes and improvements.
- Report in a timely way to governance, workforce and consumers, carers, families, supporters and kin about the outcomes and actions from complaints.
- Clearly and widely share de-identified examples of positive changes made because of feedback or complaints - for example, through discussions, posters, videos and brochures.

Tips for learning from consumer and carer feedback

Encourage all feedback including anonymous feedback - *Everything we hear from people who use our services is important, and we try to learn from it all.*

Ensure approaches are culturally safe and trauma informed.

Focus on the underlying needs behind feedback and complaints - *Could you tell me more about that? What would you like to happen now?*

Be clear about any immediate actions you can take, with the consumer's agreement.

Explain and encourage next steps if you're not the right person to act on the feedback or complaint directly.

Ensure complaint outcomes are shared with the person who made the complaint. In addition, share de-identified examples of improvements made because of feedback or complaints.

Explore opportunities for the person to share their experience and expertise more broadly, for example, by contributing to staff training or education.

Support the role of lived and living experience in systemic activities

- Actively encourage, support, and pay current and former service users for their input in service design, delivery, and improvement activities.
- Offer information, orientation and training to consumers, carers and families involved in system change activities. Where possible, offer opportunities to further develop leadership capabilities.
- Encourage formal opportunities (for example, Consumer and Carer Advisory Groups, governance committees) and informal opportunities to contribute to system change (such as community forums, or drop-in sessions). VMIAC is the peak body for consumers and have a consumer register in this link. Tandem is the peak body for families and carers and also has a participation register in this link.
- Work in Culturally safe ways with Aboriginal and Torres Strait Islander consumers, carers, families, supporters and kin contributing to system change activities (see also cultural safety principle). Good practices may include:
  - seeking advice from Aboriginal mental health workers, Social and Emotional Wellbeing (SEWB) workers or Aboriginal Liaison Officers about ensuring Culturally safe engagement
  - building relationships with Elders and community leaders and partnering with ACCHOs or other First Nations organisations
  - using informal approaches like yarning circles or sharing a meal, rather than formal advisory structures
  - preparing specific resources for Aboriginal and Torres Strait Islander consumers, carers and families that are Culturally safe and appropriate (for example, ensure language, design, and information is specific and relevant to First Nations consumers, carers and families).
- Include consumers, carers, families, supporters and kin on interview panels to ensure lived and living experience perspectives inform recruitment decisions.

Support and value the lived and living experience workforce

- Learn about relevant lived experience discipline frameworks, to self-educate about these workforces and reflect on how to recognise and value them at your service.
- Be curious about how you can collaborate with lived and living experience workforces in your role, and actively seek opportunities to learn from their perspectives.
- Recognise that lived and living experience work takes a different approach from clinical work. Give time and space for face-to-face discussions to support mutual understanding and collaboration.
- Be guided by lived and living experience workforces about where they see the most need for their involvement and where you can support and enable their work.
- Recognise that peer workers from First Nations or culturally diverse backgrounds may navigate cultural sensitivities as part of their role. Be mindful of cultural protocols such as the potential inappropriateness of discussing compulsory treatment for a community Elder.
- Identify and acknowledge power imbalances and take action to decrease differences in power. For example, include more than one lived and living experience staff member in a team/group/piece of work, speak up if lived and living experience is not involved and act on lived and living experience workforce advice about what would support their involvement.
- **Share power:**
  - Encourage lived and living experience workers as leaders or co-facilitators of programs, including wellbeing groups, psychoeducation groups, training.
  - Ensure lived and living experience workers are involved in systemic activities, such as working groups, committees, project teams, and reviewing complaints, feedback and care outcomes.
  - Analyse who isn't in the room/part of decision making. Is the diversity of your service well-represented? If no, implement strategies to improve diversity.
- **Give up power - identify activities and projects that are not currently but could be led by lived and living experience workforce and/or specific perspectives, and where lived and living experience can have decision making power.**

6. How might **services reflect** on practice?

- How do we recognise and value the lived and living experience of consumers and their carers, families and supporters, in treatment and care (for example, that they are experts in their own lives)?
- How do we learn from people with lived and living experience, so that their experiences drive change and improvement in mental health and wellbeing services?
- How can we strengthen and support the lived and living experience workforce's role in treatment and care, and in leading system change?

7. **Scenario:** building consumer leadership opportunities[16]

What happened?

A community-based mental health and wellbeing service had a consumer leadership day-to-day living program, led by a consumer consultant and a consumer peer worker with a fixed monthly budget of $500. The consumer consultant and peer worker identified that this program was a perfect opportunity for consumers to make more decisions - moving from previous approaches of *involving* consumers in decisions in how the program was run, to *empowering* consumers to drive the program within the available budget.

What actions did the service take?

The service invited all consumers who had attended any recent events to come to a monthly calendar planning meeting. The service shared the $500 budget and spending rules, then stepped back so consumers could decide - with the consumer consultant and peer worker on hand to provide any coaching or support that was requested or needed.

The consumers discussed options and decided to pursue free activities (for example, a movie day or coffee and chats in the meeting room) for a month so that the $500 could be spent for the group to attend a local cooking school and learn how to make a three-course meal.

Other activities identified by the consumers including op shopping, visits to national parks, going on walking tours or visiting public places like the Victoria Market, Arts Centre, National Gallery of Victoria and the State Library. Different consumers took the lead with different activities they were familiar with, helping others who had never been to these spaces to explore and develop new interests. Many consumers continued to visit these spaces outside of the group.

Some consumers were interested to know more about peer work and were supported to attend events to learn more. After the experience of leading their own activity group, some consumers joined the service's Consumer Advisory Committee (paid) and further developed their leadership, working on further projects like an orientation booklet for new consumers, and being paid at organisational rates to do so. One consumer later joined a sub-committee of the board.

Reflections from Commission lived and living experience staff

Working in co-design principles means giving people all the information and being open about any constraints. Paying people recognises their time and lived experience and expertise is valuable.

Which other principles were engaged?

Mental health and wellbeing principles: diversity of care, dignity and autonomy, supported decision making

How would you approach this situation?

What might you do differently?

16 Note: The scenarios in this guidance are adapted from real examples. These simple scenarios focus on the application of one principle and are intended to show that applying the principles is not always complicated. Scenarios that address the principles in more complex situations and ways are available in implementation resources on the Commission's website.

8. Where can I find **more information?**

Department of Health (2021) Mental Health Lived Experience Engagement Framework https://www.health.vic.gov.au/publications/mental-health-lived-experience-engagement-framework

Harm Reduction Victoria (2025) Harm Reduction Lived Experience Framework https://www.hrvic.org.au/_files/ugd/ebb8bf_f1d2347fd1c64956a7793998530767a1.pdf?index=true

Mental Health Coordinating Council (2022) Recovery Oriented Language Guide https://mhcc.org.au/wp-content/uploads/2022/07/Recovery-Oriented-Language-Guide-Mental-Health-Coordinating-Council-2022.pdf

Our consumer place (2012) - Psychobabble: the little red book of psychiatric jargon https://www.ourcommunity.com.au/files/OCP/PsychobabbleFeb2012.pdf

Self Help Addiction Resource Centre (2025) Alcohol and Other Drug (AOD) Family Lived Experience Workforce Discipline Framework https://www.sharc.org.au/wp-content/uploads/2025/03/AOD-Family-Lived-Experience-Workforce-Discipline-Framework.pdf

Self Help Addiction Resource Centre (2025) Alcohol and Other Drug (AOD) Lived Experience Workforce Discipline Framework https://www.sharc.org.au/wp-content/uploads/2025/03/AOD-Lived-Experience-Workforce-Discipline-Framework.pdf

Tandem and the Carer Lived Experience Workforce (2025) Mental Health Family Carer Lived Experience Workforce Discipline Framework https://tandemcarers.org.au/Common/Uploaded%20files/Publications/Mental%20Health%20Family%20Carer%20Lived%20Experience%20Discipline%20Framework.pdf

University of Melbourne (2025) Mental Health Consumer Lived Experience Workforce Discipline Framework https://healthsciences.unimelb.edu.au/__data/assets/pdf_file/0020/5242142/384076-DOH-MH-Consumer-framework-WEB-WCAG-5.0.pdf