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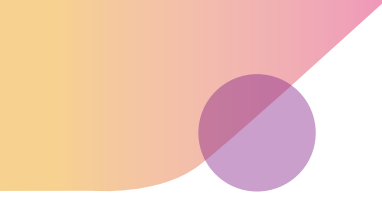
# The Lived Experience Governance Framework

Centring People, Identity and Human  
Rights for the Benefit of All

Prepared by



July 2023



### Acknowledgement

The National Mental Health Consumer and Carer Forum and the National Primary Health Network Mental Health Lived Experience Engagement Network acknowledge the Traditional Custodians of the lands and waters on which we work and live on across Australia. We recognise their continuing connection to land, waters, culture and community. We pay our respects to Elders past and present.

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## A Vision for the Future<sup>1</sup>

We believe unequivocally that now is the time for lived experience leadership to be developed and embedded in our systems. The need is visible and the conditions for change are right. The vision for lived experience leadership and future services are where humanity and connection are centred and where people with lived experience meaningfully and equally contribute at all levels, to the point that it becomes the norm.

Through taking action together a more holistic approach will guide change, and ensure that our language, power, and mindsets, shift beyond biomedical and ‘illness’ dominated narratives. Upholding rights, giving control to people to determine their own lives and authentic co-design are essential foundations of the changes we seek.

Systems are strengthened when discrimination and tokenism are minimised and where peoples’ dignity is prioritised. Lived experience leadership across the system, including by and with people with lived experience, is core to this vision being realised and is itself a key driver of the broader systems change that the mental health and social services sector require<sup>2</sup>.

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<sup>1</sup> This ‘vision’ was developed in 2021 by the SA Lived Experience Leadership Advocacy Network (LELAN) and UniSA’s Mental Health and Suicide Prevention Research and Education (MHSPRE) Group, in partnership with over 40 mental health, social sector and lived experience leaders. As part of the Activating Lived Experience Leadership (ALEL) Project they worked together to determine actions that can be taken to embed and leverage lived experience leadership to transform systems. More information, resources and background reports can be accessed via the project page at [www.lelan.org.au/alel](http://www.lelan.org.au/alel).

<sup>2</sup> Hodges, E., Loughhead, M., McIntyre, H. and Procter, N.G. 2021, Strengthening lived experience leadership for transformative systems change: A South Australian consensus statement, SA Lived Experience Leadership and Advocacy Network and University of South Australia, Adelaide.



# A Lived Experience Governance Primer

## The definition of lived experience governance

Lived experience governance intentionally embeds organisational cultures and systems that give primacy to centring or being led by lived experience perspectives, principles, and ways of working in the decision-making, oversight and evaluation of systems, structures, policies, processes, practices, programs and services.

Lived experience governance aligns with and supports other forms of governance. It does so while ensuring that the voices and contributions of people with lived experience are central to the effective governance and management of organisations and systems. It is an essential component in, but not limited to, peer led services and programs, and is applicable across diverse communities and sectors, in both clinical and non-clinical settings.

## Lived experience governance core, foundations and domains

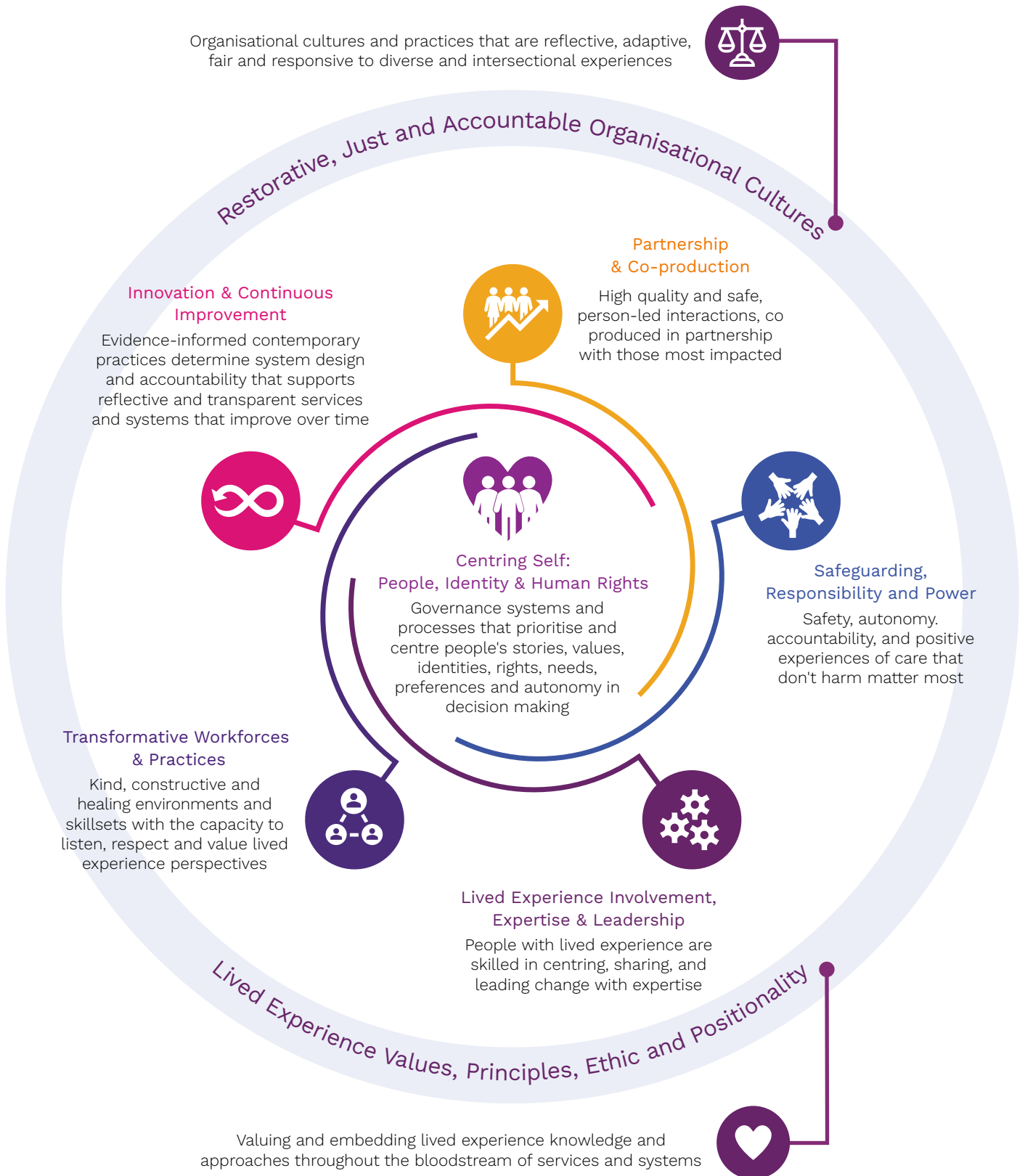
The core of lived experience governance is *Centring Self: People, Identity and Human Rights*. Surrounding this are two wrap-around foundational constructs and aligned ways of working that must be embedded across all other components of the Lived Experience Governance Framework (the Framework) for its full potential to be realised. The integration of *Restorative, Just and Accountable Organisational Cultures* and *Lived Experience Values, Principles, Ethic and Positionality* across the Framework is essential to the evolution of care and organisational cultures, structures and practices required for transformative systems change.

The Framework identifies key areas of focus required to develop and maintain high-quality organisational performance that centres and values the experiences, insights, perspectives and contributions of people interacting with or being supported by systems, structures, policies, processes, practices, programs and services. These key areas of focus are organised into five inter-connected and interdependent domains: *Partnership and Co-Production; Safeguarding, Responsibility and Power; Lived Experience Involvement, Expertise and Leadership; Transformative Workforces and Practices; and Innovation and Continuous Improvement*.

## What success looks like

The ways that organisations approach lived experience governance will be proportionate to the needs and size of the organisation, the complexity of the environments that they operate within, their aspired influence and the responsibility they take on to truly embed human rights and person-directed and -led approaches. The people that interact with or are supported by organisations are in the best position to judge success and the ways that is best measured. Below are indicators of success co-created throughout the development of the Framework.

The diagram below depicts the essential components of lived experience governance, as well as the desired outcomes of the approach when done well.





# Introduction

The Lived Experience Governance Framework ('the Framework') responds to calls from the mental health and other sectors for changes in the way systems are governed to align them more strongly with human rights approaches and to meaningfully embrace lived experience. To transform systems and improve lives, a formal framework is needed to embed lived experience perspectives, values, principles, expertise and leadership in all aspects of governance. Its applicability and reach span a spectrum of settings and sectors, including and beyond health systems, structures, policies, processes, practices, programs and services and peer-led initiatives.



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There is an unrepentant demand for a shift from words to deeds. But that begs the question, what would a system governed on the basis of lived experience, equity, human rights and justice look like? What is involved in getting there? Who do we need at the table? What kinds of tables do we need?

Interview  
Participant

Embodying the principles of co-production, the Framework was developed through extensive collaboration with people with lived experience in both designated and non-designated positions, and people with service, system and governance knowledge and experience. Contributors spanned frontline staff to executives and included clinical, policy, project and advocacy roles. Contributions were made through individual interviews, thinktank conversations, co-design sessions, formal and informal conversations and commenting on early drafts of the Framework. Direct quotes from people who contributed are shared throughout the Framework, these include words from Aboriginal and Torres Strait Islander peoples.

The result is a Framework that upholds lived experience as an essential component of governance and decision-making for organisations and systems to ensure the strength of lived experience organisations, programs and peoples are visible and valued within and alongside other governance approaches. It adopts a truly person-led and human rights focus, with the overarching intent of reducing potential for harm and improving lives.

## Purpose of a Lived Experience Governance Framework

The Framework provides a mechanism for organisations and sector leaders to have a clear understanding and oversight of expectations, objectives, accountabilities and performance that ensures the voice, contributions and decision-making power of people with lived experience is evident at all levels. It is a transformational tool that organisations can adopt, scale and customise to transform system, service and professional cultures, mindsets and practices that benefits all.

The intended results of implementing the Framework are systems and organisations that uphold human rights and embed lived experience to enhance the quality and safety of systems, services and programs. Human rights are universal and inalienable, and all people have the right to the highest attainable standard of health<sup>3</sup>.

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<sup>3</sup> Committee on Economic, Social, and Cultural Rights (CESCR), 2000, CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12), Doc. E/C.12/2000/4



Embedding human rights into governance, service commissioning and funding, systems leadership and management, regulatory oversight, service models, and workforce development is essential<sup>4</sup>.

The Framework challenges the notion that clinical governance's current approach to risk is the only way that safe and effective practices and 'treatment' can be achieved and maintained. A key point of difference is that lived experience governance centres the person's agency to make choices for and have control of their life, with a lens to dignity, equity, rights and justice. For care to be truly person-centred, person-directed and ideally person-led, a shift in conceptualising experiences, practices and organisational cultures away from the dominant perspective regarding capacity, risk aversion and mitigation is required. The Framework demonstrates that it's possible to do this by understanding there is a responsibility to, not just for or over, people interacting with or being supported by systems, structures, policies, processes, practices, programs and services.

Embedding lived experience is more than merely including lived experience perspectives in service design and delivery. It is more than ticking a box to pass accreditation or meet minimum requirements of commissioning or funding criteria. It speaks to elevating voices and embracing the expertise and leadership of people with lived experience to influence change and weaving that through all aspects of an organisation's policies, activities, workforce, decision-making and governance.



*Thinking about some of those things like choice and control and mutuality and peer support, how can you apply those principles in a governance context? Because I do think the way that governance is done is typically very hierarchical and very kind of western models of what governance and community and organisations look like.*

Interview  
Participant

It is through embedding lived experience that systems, structures, policies, processes, practices, programs and services become more responsive, leading to increased trust, improved outcomes, and better lives because harm is avoided and healing is prioritised. Proven benefits<sup>5</sup> of person-centred care being realised include better experiences and outcomes for people and communities receiving care as well as increased wellbeing and morale for providers of care. Better value care is also delivered through reduced cost of care that is safer, of a higher quality, and provides better outcomes that people want to access.

The Framework articulates that people interacting with or being supported by services and organisations provide stewardship and are essential. Whilst person-centred governance is desirable, the ultimate goal of the framework is to move governance towards person-directed and ultimately person-led organisational cultures, systems, structures, policies, processes, practices, programs and services.

It is fearless and courageous, boldly articulating the essential components of governance that will improve systems, services, communities, and ultimately lives.

<sup>4</sup> Katterel, S. & Maylea, C. 2021, Keeping human rights in mind: embedding the Victorian Charter of Human Rights into the public mental health system, Australian Journal of Human Rights, DOI: 10.1080/1323238X.2021.1943300

<sup>5</sup> Australian Commission on Safety and Quality in Health Care (ACSQHC), 2018, Review of the key attributes of high-performing person-centred healthcare organisations, Sydney.



*You know the waters will get choppy; you'll get pushed in lots of different directions. But if you don't have a compass, you won't know where you're going in those situations.*

Interview  
Participant

## How to use the Framework

The Framework identifies key governance structures and processes required to develop and maintain high-quality organisational interactions and performance that values and embeds lived experience. Within the Framework these key areas of focus are underpinned by two foundational concepts and are organised into five domains of lived experience governance.

The Framework is purposefully broad. It can be applied and adapted across a variety of contexts, service settings and sectors, including though not limited to acute, government and non-government primary, secondary and tertiary care, peer-led and other community-based activities, programs or services that impact mental health and social and emotional wellbeing, as well as those related to alcohol and other drug use, homelessness and housing instability and domestic and family violence. Every group and organisation will have their own change journey and continuous improvement processes that impact how the Framework may be utilised, adapted or scaled.

The intent is that the Framework domains and concepts provide overarching guidance to conceptualisations and approaches that give primacy to the rights, needs, preferences, autonomy and decision-making power of people interacting with or being supported by an organisation.

When applying the concepts, it is critical that the needs and perspectives of the person most impacted by the interaction or care experience are centred. Lived experience is sometimes used as an overarching term that combines the experiences of 'consumers', or people who have accessed services and are at the centre of interactions, support or care, with the experiences of 'carers', family, kin and other supporters of choice. Whilst it is acknowledged that some carers also have personal lived experience, there are some situations where consumer and carer perspectives are in alignment and other times where there is clear opposition. Significant differences in perspective, and nuanced understandings and practices are required which recognise, account for and include consumer and carer perspectives.

In order to authentically represent a perspective with integrity in governance spaces, both carer and consumer experiences *must be recognised as independent and separate of each other and both be given opportunities for involvement and representation matched to the context and issue being explored*<sup>6</sup>.

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<sup>6</sup> Hodges, E. & Reid, A. 2021, A guide for enabling lived experience involvement and leadership to thrive and have impact in your organisation. SA Lived Experience Leadership & Advocacy Network (LELAN), Adelaide, accessed at [https://www.lelan.org.au/wp-content/uploads/2021/08/Guide\\_Enabling-LEx-to-Thrive-in-Your-Organisation.pdf](https://www.lelan.org.au/wp-content/uploads/2021/08/Guide_Enabling-LEx-to-Thrive-in-Your-Organisation.pdf)

## What do we mean by lived experience?

‘Lived experience’ has been a contested and difficult to define concept. As use of the term has grown across a range of sectors and service settings there are sometimes questions about what type or how much experience is enough, and whether disclosure from people about their own lived experiences has the same relevance and weight as people who intentionally use their lived experience for change.

Broadly speaking, lived experience has been described as *the things that someone has experienced themselves, especially when these give the person a knowledge or understanding that people who have only heard about such experiences do not have*<sup>7</sup>. It has also been described as belonging to *people who have gained knowledge through direct, first-hand involvement in everyday events, rather than through assumptions and constructs from other people, research, or media*<sup>8</sup>.

In order to enable and embed lived experience governance, it is essential to determine what lived experience means in this context. It is the responsibility of lived experience communities to define, clarify and strengthen the definition of lived experience and drive collective action, so that it is not diluted, co-opted or lost before it even gains full traction and has its potential realised.

For the purposes of the Framework, ‘lived experience’ is defined as personal experience(s) of a particular issue, such as mental health challenges or alcohol and other drug use, and the living despite *that have caused life as we knew it to change so significantly we have to reimagine and redefine ourselves, our place in the world and our future plans. It is informed by the expertise, the collective knowledge of the lived experience movement and, importantly, it’s about learning how to use those experiences in a way that’s useful to other people*<sup>9</sup>.

In the implementation of the Framework, there is a real need and opportunity for forward-focused lived experience leadership that provides vision, purpose and builds momentum by, for and with the lived experience movement.



*Keeping the integrity of lived experience, disciplines, and perspectives in the service system. ... What’s happening now is that systems are just recreating in their own image, and so there needs to be some sort of discipline and integrity that people with lived experience and the system have control over.*

Interview  
Participant

As the lived experience movement grows and integration of their expertise within systems, it is essential to acknowledge the emotional responsibility and potential burden on people with lived experience that their involvement and work has. Lived experience is not something that people can turn on or off at will, and it has an ongoing impact on people’s lives, work and actions. It is important that people with lived experience determine the extent of their involvement and for their disclosure decisions to be respected.

<sup>7</sup> Cambridge University Press, 2023, accessed at <https://dictionary.cambridge.org/us/dictionary/english/lived-experience>

<sup>8</sup> Chandler, D. & Munday, R. 2011, A Dictionary of Media and Communication, Oxford University Press, <https://doi.org/10.1093/acref/9780199568758.001.0001>

<sup>9</sup> Byrne, L. & Wykes, T. 2020, A role for lived experience mental health leadership in the age of Covid-19, Journal of Mental Health, 29:3, 243-246, DOI: 10.1080/09638237.2020.1766002

## Defining Lived Experience Governance And Where It Fits



Understanding how lived experience governance sits and fits in relation to other forms of governance is essential for successful implementation.

Lived experience governance exists as a separate and equally important component of an organisation's corporate governance and strategic processes and structures.

Lived experience governance is aligned with and complementary to other essential corporate governance mechanisms that support safe, effective, person-centred practice and decision-making<sup>10</sup>.

All governance should be person-centred and underpinned and informed by lived experience values, principles and perspectives.



*Good governance is saying this current system that has been built is what is causing harm. And we need to be creating and affirming values and practices that resist that abuse and oppression and encourage safety, encourage accountability. We need to encourage self-determination, encourage mentoring, and encourage other ways to continue to be part of this movement.*

Thinktank Participant

### The definition of lived experience governance

Lived experience governance intentionally embeds organisational cultures and systems that give primacy to centring or being led by lived experience perspectives, principles, and ways of working in the decision-making, oversight and evaluation of systems, structures, policies, processes, practices, programs and services.

Lived experience governance aligns with and supports other forms of governance. It does so while ensuring that the voices and contributions of people with lived experience are central to the effective governance and management of organisations and systems. It is an essential component in, but not limited to, peer led services and programs, and is applicable across diverse communities and sectors, in both clinical and non-clinical settings.

<sup>10</sup> A more detailed exploration of governance and various approaches is included in Appendix One of the Framework.



*Lived experience governance is a means and measure for authenticity, accountability of practice, position, and perspective to interface with spheres of influence and systems in a purposeful way.*

Thinktank  
Participant



*It is ensuring the servicing system meets the individual, rather than individual having to meet the service and the system.*

Interview  
Participant

Lived experience governance is not just an accountability mechanism, it demands that the dignity, rights and self-determination of people, and the stewardship and leadership of people with lived experience are embedded in the bloodstream of an organisation which changes organisational cultures and, ultimately, changes lives.

## Connections and linkages

It is important to acknowledge the different regulatory structures and systems across settings and sectors, including public, private, primary health care and community-managed sectors. A number of national safety and quality standards and accreditation programs highlight the importance of governance over the services provided and promote partnerships with people with lived experience in effective, safe and high-quality care.

Implementation of the Framework can assist organisations to meet the requirements of the Clinical or Practice Governance Standard and a Partnering with Consumers Standard found within:

- The National Safety and Quality Health Service (NSQHS) Standards.
- Primary and Community Healthcare Standards that apply to services that deliver healthcare in a primary and/or community setting, in particular, the Partnering with Consumers Standard.
- National Safety and Quality Mental Health Standards for Community Managed Organisations.

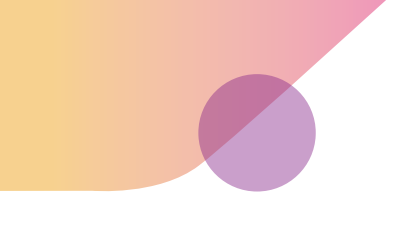
The Framework aligns with the core module of the NDIS Practice Standards and Quality Indicators as defined in the National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018<sup>11</sup> and other human rights measures<sup>12</sup>.

The Framework provides a mechanism to create conditions required for sustainable mental health and wellbeing system reform and transformation recommendations from the Royal Commission into Victoria's Mental Health System<sup>13</sup>, the Productivity Commission's Inquiry into Mental Health and the more connected and compassionate approach called for within the National Suicide Prevention Advisor's Final

<sup>11</sup> National Disability Insurance Scheme (Code of Conduct) Rules, 2018, accessed at <https://www.legislation.gov.au/Details/F2018L00629>

<sup>12</sup> Convention on the Rights of Persons with Disabilities, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008), article 4(3).

<sup>13</sup> State of Victoria, Royal Commission into Victoria's Mental Health System, Final Report, Summary and recommendations, Parl Paper No. 202, Session 2018–21 (document 1 of 6).



Advice<sup>14</sup>. It informs the necessary governance and oversight, leadership, accountability and co-production across governments and diverse lived experience communities to improve systems, organisational cultures, structures, policies, processes, practices, programs and services.

Person-centred governance structures are essential to improve quality of organisational processes and involve people with lived experience at all levels of the organisation<sup>15</sup>. It improves the value delivered by services, systems, and programs by achieving better outcomes at lower overall cost to health systems and the community.

To do so, clear accountabilities are required, and all governance and operational decisions should explicitly consider and prioritise rights, needs, preferences autonomy and decision-making power of people they serve.

### Tensions and approaches to risk and decision-making

There are inherent tensions in governance, particularly in relation to mental health and suicide prevention across clinical service settings and different legislative environments where the rights of people are actively breached. In these contexts different appetites for risk and safety promoting approaches are adopted depending on perspective, positionality and concern for ramifications for providers of care or people making decisions and organisations over the rights, needs, preferences and autonomy of a person interacting with or being supported by them. One viewpoint may propose intervention is required if someone is unwell or there is a risk that they may do something harmful to themselves or others. This contrasts with an approach that assumes that the person has the dignity and capacity to make, or be supported to make, informed decisions and have responsibility for their own wellbeing and life.

It is critical to acknowledge the risks associated with intervening and removing decision-making power and rights away from people experiencing distress. The harm of this approach is often unrecognised, underassessed and not spoken about or safeguarded. Concerted effort, accountability mechanisms and redress processes to address repeated systems failings and preventable harm must be prioritised in design, delivery and evaluation of all systems, structures, policies, processes, practices, programs and services.



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*If you're going to have a conversation about what the risks are and the risk management approach that is used to manage those risks, involve people with lived experience in defining the risks and defining the risk mitigation strategies.*

Interview Participant



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*It's about how to manage risk and how do we provide a service that is safe. And that's how I see it. It's really simple. But if they're using the coroners as the benchmark for what they do, they're way off track.*

Thinktank Participant

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<sup>14</sup> Commonwealth of Australia, 2020, National Suicide Prevention Final Advice. Executive Summary.

<sup>15</sup> Australian Commission on Safety and Quality in Health Care (ACSQHC), 2018, Review of the key attributes of high-performing person-centred healthcare organisations, Sydney.

Safety cultures and practices across organisations and services that promote connection, choice and responsibility to and not for or over<sup>16</sup> people are imperative. Such approaches must operate and be nurtured at all times in relationship with people interacting with or being supported by services, rather than being focused on more intently when risk is recognised or perceived. The rationale and evidence for such approaches, as well as guidance documents for enabling them, must be sought out and adopted.<sup>17 18 19 20</sup>

The Lived Experience Governance Framework provides a guidepost across the interrelated foundational concepts and domains to assist leaders, organisations and systems to transform practice and navigate the complexities that exist in this space. It invites everyone to approach risk differently, shifting toward safety culture and practices most supportive of recovery, healing and autonomy of people interacting with or being supported by systems, structures, policies, processes, practices, programs and services.



*You've got to weigh out the benefit of being able to provide a service that is peer-led, where people feel comfortable and trusting to come, to a service that is so clinically-led that people are not going to be wanting to be there. ... All the way through we've been able to show good decision-making around the decisions that we've made. Things will go wrong, there is no doubt, touch wood it won't be any time soon. There is no doubt at some point something will happen. It's just a fact of life in the services that we're operating, at some point there will be some kind of adverse event. ... And all we can do is show that we have made considered informed decisions around what we've done, and I think we can show that all the way along the process. We have to have a bit of risk appetite, because otherwise we will never move forward. If we're not prepared to have a bit of risk appetite, we're going to sit in the 1950s forever.*

Thinktank  
Participant

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<sup>16</sup> Alternatives to Suicide Charter.

<sup>17</sup> Perkins, R. & Repper, J. (2016). Recovery versus risk? From managing risk to the co-production of safety and opportunity in Mental Health and Social Inclusion, vol 20(2), pp.101-109. DOI: 10.1108/MHSI-08-2015-0029

<sup>18</sup> Fletcher, J., Buchanan-Hayen, S., Brophy, L., Kinner, S.A. & Hamilton, B. (2019). Consumer Perspectives of Safewards Impact in Acute Inpatient Mental Health Wards in Victoria, Australia in Frontiers in Psychiatry. DOI: 10.3389/fpsy.2019.00461

<sup>19</sup> Boardman, J. & Roberts, G., (2014). Risk, Safety and Recovery. Centre for Mental Health and Mental Health Network, NHS Confederation.

<sup>20</sup> Carroll, A. & McSherry. (2021). Risk management in the era of recovery and rights in British Journal of Psychological Advances, vol. 27, pp. 394-404. DOI: 10.1192/bja.2020.88

## Lived Experience Governance Core, Foundations and Domains

Lived experience governance is achieved through commitment and action across all levels of an organisation to all components of the Framework. It is supported by flexible structures and processes that adapt to the rights, needs and preferences of people interacting with or being supported by them, the complexity of the organisation as well as the environment they exist and intersect within at that particular moment in time.

The core of lived experience governance is *Centring Self: People, Identity and Human Rights*. Surrounding this are two wrap-around foundational constructs and aligned ways of working that must be embedded across all other components of the Framework for its full potential to be realised. The integration of *Restorative, Just and Accountable Organisational Cultures* and *Lived Experience Values, Principles, Ethic and Positionality* across the Framework is essential to the evolution of care and organisational cultures, structures and practices required for transformative systems change.

The Framework identifies key areas of focus required to develop and maintain high-quality organisational performance that centres and values the experiences, insights, perspectives and contributions of people interacting with or being supported by systems, structures, policies, processes, practices, programs and services. These key areas of focus are organised into five inter-connected and interdependent domains: *Partnership and Co-Production*; *Safeguarding, Responsibility and Power*; *Lived Experience Involvement, Expertise and Leadership*; *Transformative Workforces and Practices*; and *Innovation and Continuous Improvement*.





## Core to Lived Experience Governance



### Centring self: people, identity and human rights

The Framework draws attention to and is informed by aspects of self, personhood and human rights<sup>21</sup> that transcend lived experience governance and have relevance for all forms of governance.

Grounded in thousands of years of experiences and ways of knowing, being and doing, Aboriginal and Torres Strait Islander peoples have led the way in embracing and centring a collective and holistic approach to self and wellbeing. Built upon the foundation of connection and aligned with the domains within the Framework, the diagram below<sup>22</sup> describes some of the interconnected cultural domains of wellbeing from an Aboriginal and Torres Strait Islander perspective<sup>23</sup>.



When adopted across leadership and governance systems, structures, policies, processes, practices, programs and services, this framing benefits all and is in true alignment with lived experience values and principles. The Framework does not seek to co-opt or steal, but rather amplify this approach that views

<sup>21</sup> Convention on the Rights of Persons with Disabilities, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008), article 12(2).

<sup>22</sup> Gee, G., Dudgeon, P., Schultz, C., Hart, A., & Kelly, K. (2014). Social and Emotional Wellbeing and Mental Health: An Aboriginal Perspective. In P. Dudgeon, M. Milroy, & R. Walker. (Eds.), Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice – Revised Edition (p.55-68). Canberra: Commonwealth of Australia. <https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/working-together-second-edition/wt-part-1-chapt-4-final.pdf>

<sup>23</sup> This conception of self is grounded within a collectivist perspective that views the self as inseparable from, and embedded within, family and community. © Gee, Dudgeon, Schultz, Hart and Kelly, 2013 Artist: Tristan Schultz, RelativeCreative

the self as inseparable from, and embedded within, family and community.<sup>24</sup>

These interconnected and interdependent aspects of self, impact on access to relationship, support, recognition, identity, power, self-determination and decision-making authority. These influence peoples experience of their own personhood and humanity, as well as how they are perceived by and responded to by others, and have real effects on experiences of safety within mental health services.<sup>25</sup> They are spotlighted here with a recognition that they should ideally inform all governance processes. With a focus on inclusion, diversity, intersectionality, culture and Aboriginal and Torres Strait Islander self-determination, lived experience practice and governance need to be understood from and account for different lenses of experience, community and identity, as well as the lasting effects of systemic oppression that many people continue to live with.



*There's so much that we can learn from community-led responses across queer communities, Aboriginal and Torres Strait Islander communities. There's so much about the way that we think about, you know, individual experience and mental health that doesn't talk to collectivist cultures. There's so much that we do that's inaccessible for people.*

Interview  
Participant

## Diversity and intersectionality

Embedding and valuing diversity and intersectionality is not only foundational to lived experience governance but to safer, more equitable and just societies.

Our identity, and therefore sense of self and who we are, is shaped by how we interact with and relate to the people, communities and systems that surround us, and this is informed by the factors that make us diverse as people and the ways each of these factors intersect and layer over each other. This diversity may include but is not limited to: age and generation; race and ethnicity; gender identity and modality; sexual orientation; religious and spiritual beliefs; where one lives, whether in a metropolitan area or regional, rural, or remote location; level of disability, and so much more. While different forms of diversity shape our experiences within a specific context, intersectionality allows for peoples' identities and experiences to be better understood by viewing them holistically at the same time.

*Intersectionality is a lens through which you can see where power comes and collides, where it interlocks and intersects<sup>26</sup>. It occurs when people face multiple forms of discrimination or oppression simultaneously and their experiences cannot be fully understood by looking at just one aspect of self. Instead, intersectionality recognises that the intersections of various demographics, labels and identities create*

<sup>24</sup> Gee, G., Dudgeon, P., Schultz, C., Hart, A., & Kelly, K. (2014). Social and Emotional Wellbeing and Mental Health: An Aboriginal Perspective. In P. Dudgeon, M. Milroy, & R. Walker. (Eds.), Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice – Revised Edition (p.55-68). Canberra: Commonwealth of Australia. <https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/working-together-second-edition/wt-part-1-chapt-4-final.pdf>.

<sup>25</sup> Cutler, N., Sim, J., Halcomb, E. & Stephens, M. (2020). Understanding how personhood impacts consumers feelings of safety in acute mental health unit. International Journal of Mental Health Nursing. DOI: 10.1111/inm.12809

<sup>26</sup> Kimberlé Crenshaw on Intersectionality, More than Two Decades Later (2017) <https://www.law.columbia.edu/news/archive/kimberle-crenshaw-intersectionality-more-two-decades-later>



unique experiences of marginalisation, power imbalance and privilege<sup>27</sup>.

People's identity and experiences influence their understanding of, access to and interactions with systems. Adopting a holistic and deeper understanding of self provides an opportunity for strategic exploration of which factors influence the quality, safety and effectiveness of these interactions.

At a governance level an understanding of diversity and intersectionality allows for services to validate and view a person and their experiences in their entirety. It leads to better outcomes and allows for interrogation of the structural ways that different forms and intersections of diversity are valued to different degrees.

### Centrality of culture

Any consideration of governance without careful and purposeful inclusion of the cultural needs of Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities is incomplete. This is not just a matter of moral imperative, these principles are reflected under international human rights declarations<sup>28</sup> and various domestic human rights laws<sup>29</sup>. When referring to cultural groups such as Aboriginal and Torres Strait Islander peoples and their connection to culture it refers to the *body of collectively shared values, principals, practices and customs and traditions*<sup>30</sup> they identify with and includes systems of knowledge, law and practices that comprise their heritage. Culture is core to and inseparable from a person's lived experience that shapes them, their worldviews, positionality, values, beliefs, attitudes, interactions with others and experiences of marginalisation.

Culture cannot be considered without also speaking about racism. Racism is a form of discrimination that is based on race, ethnicity, nationality, or other factors, and can result in unfair treatment, exclusion, and marginalisation of individuals or groups. Efforts to combat racism and promote human rights require comprehensive and sustained actions at individual, institutional, and societal levels. This includes addressing discriminatory governance policies, practices, and attitudes, promoting inclusive and diverse societies, protecting the human rights of all individuals regardless of their race or ethnicity, and promoting awareness, education, and respect for human rights principles.

To address systemic racism and oppression, explicitly embedding anti-oppressive and culturally responsive governance systems, structures, policies, processes, practices, programs and services is non-negotiable. Such measures benefit diverse cultural groups, particularly those that have experienced the greatest harms which includes Aboriginal and Torres Strait Islander peoples and people from other cultures that have fled their country of origin as refugees. If the aim is to achieve safe, accessible, person-directed and informed care that is grounded in rights and self-determination, then cultural responsiveness is the practice to enable it.

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<sup>27</sup> Crenshaw, K., (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. University of Chicago Legal Forum, 139-167.

<sup>28</sup> United Nations Declaration on the Rights of Indigenous Peoples, GA Res 61/295, A/RES/47/1 (2007).

<sup>29</sup> Charter of Human Rights and Responsibilities Act 2006 (Vic), s 19; Human Rights Act 2019 (Qld), 27; Human Rights Act 2004 (ACT) s 27(2).

<sup>30</sup> Gee, G., Dudgeon, P., Schultz, C., Hart, A., & Kelly, K. (2014). Social and Emotional Wellbeing and Mental Health: An Aboriginal Perspective. In P. Dudgeon, M. Milroy, & R. Walker. (Eds.), Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice – Revised Edition (p.55–68). Canberra: Commonwealth of Australia. <https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/working-together-second-edition/wt-part-1-chapt-4-final.pdf>



*I think also, people in the lived experience sector, especially those who are white, need to self-educate and be aware of the saviour complex - how this may unintentionally show up in our advocacy efforts. Internalised prejudice is something we need to be transparent about and unlearn.*

Interview  
Participant

## Aboriginal and Torres Strait Islander self-determination

It is essential that governance structures recognise and ameliorate historical and ongoing harmful impacts of policies and practices. The Aboriginal and Torres Strait Islander Lived Experience Centre definition<sup>31</sup> of Aboriginal and Torres Strait Islander Lived experience brings attention to this.

*A lived experience recognises the effects of ongoing negative historical impacts and or specific events on the social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples. It encompasses the cultural, spiritual, physical, emotional and mental wellbeing of the individual, family or community.*

The above definition simultaneously provides an example of intersectionality through prompting consideration of the cultural understandings within Aboriginal and Torres Strait Islander communities. These cultural understandings of social and emotional wellbeing make lived experiences of suicide among Aboriginal and Torres Strait Islander peoples unique compared to non-Aboriginal and Torres Strait Islander people's lived experiences of suicide.

*People with lived experience of suicide are those who have experienced suicidal thoughts, survived a suicide attempt, cared for someone through a suicidal crisis, been bereaved by suicide or having a loved one who has died by suicide, acknowledging that this experience is significantly different and takes into consideration Aboriginal and Torres Strait Islander peoples ways of understanding social and emotional wellbeing.*

As Australia's first peoples, the right to self-determination has particular application to Aboriginal and Torres Strait Islander peoples. It refers to genuine decision-making power and responsibility for what happens on Aboriginal and Torres Strait Islander peoples' lands, in their affairs, in their governing systems, and in their development strategies. It means having meaningful control over one's own life and cultural wellbeing. As decision-making power and responsibility move from external authorities into the hands of Aboriginal and Torres Strait Islander peoples, self-determination grows. Racism against Aboriginal and Torres Strait Islander peoples is deeply rooted in colonial history, dispossession, and ongoing social, economic, and political inequalities. It has severe impacts on the health, well-being, and social outcomes of Aboriginal and Torres Strait Islander peoples, including their physical and mental health, social and emotional well-being, educational attainment, employment opportunities, and access to basic services<sup>32</sup>.

Addressing racism against Aboriginal and Torres Strait Islander and other peoples require systemic and structural changes, including recognition and respect for Indigenous peoples' rights, promotion

<sup>31</sup> Aboriginal and Torres Strait Islander Lived Experience Centre, 2020, Black Dog Institute accessed at <https://www.blackdoginstitute.org.au/education-services/aboriginal-and-torres-strait-islander-network/>

<sup>32</sup> Bodkin-Andrews, G., Paradies, Y., Parada, R. H., Denson, N., Priest, N., & Bansel, P. (2012). Theory and research on bullying and racism from an Aboriginal Australian perspective. Regional And Global Cooperation In Educational Research: Proceedings Of The 42nd Joint Australian Association For Research In Education And Asia-Pacific Educational Research Association Conference, 2-6 December, 2012, University Of Sydney, N.S.W., 1-14. <https://files.eric.ed.gov/fulltext/ED544515.pdf>

of cultural safety and inclusion, addressing historical and contemporary injustices, and empowering Aboriginal and Torres Strait Islander peoples to have a meaningful voice and participation in governance and decision-making processes.

The leadership, cultural practices and expertise of Aboriginal and Torres Strait Islander peoples is critical to improving outcomes and building culturally responsive, safe and effective governance systems.

## Foundations to be Embedded Across All Domains



### Lived experience values, principles, ethic and positionality

The values, principles, ethic and positionality of lived experience are foundational to governance. How governance is implemented through practice and process, is as important as the domains of lived experience governance themselves.

Lived experience values, principles, ethic and positionality underpin all aspects of governance. They are the lens through which people with lived experience work and live. Centring lived experience requires everyone involved to bring a particular ethic and values focus to relationships and interactions.

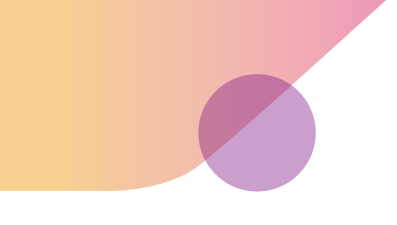
Demonstrating commitment to and embodying lived experience values and principles is a matter of personal, professional and socio-political ethic and responsibility. Ethic encapsulates the knowing and being that a person brings to an interaction. Positionality explores how power differences can shape access and identities in society and shapes the way the world is seen in relation to those we interact with.

The basic premise of governance as a framework by which decisions are made hold true for lived experience governance. Additionally, it is the ways of working and the principles that determine and influence decision-making, that are different from other forms of governance. It's about prioritising people's stories, values, identities, rights, needs, preferences and autonomy in decision-making.



*What actually is lived experience work? ... It's a worldview. It's a different worldview. And you either have that, or you don't. Or you develop it or whatever, but you can either sit within that worldview, or you just can't. And I think, when you think about it as a different worldview, then it's actually, it's not one thing, it's a reconceptualisation of governance... It's not one point of adaptation from what we currently do, ...it's to have oversight and decision-making that is informed by that worldview. That feels open and expansive, possibly a bit endless. ... That's the way we have to think about the work. It's not how we're adapting from, but what're we creating from that worldview that is much better, more human centred, more collaborative, more intersectional, more expansive kind of systems and solutions for healing.*

Interview  
Participant



The values and principles that apply to people with lived experience must be applied to all, including the lived experience (peer) workforces and other broader workforces, service settings and systems. Ultimately, it is not solely a person's lived experience that matters, but the humanity and self brought to each interaction and experience and how they are supported to contribute to or lead the planning, design, implementation and evaluation of changes they seek in an ongoing way.

Extensive work went into the development of the National Lived Experience (Peer) Workforce Development Guidelines<sup>33</sup> which clearly articulate the core values and principles of the lived experience (peer) workforces. The Framework does not duplicate but builds upon these existing values and principles to highlight how they apply and relate to governance outlined in the following tables.

The National Lived experience (Peer) Workforce Development Guidelines do not specifically reference cultural safety. This Lived Experience Governance Framework identifies cultural responsiveness as a core lived experience principle.

## Core Lived Experience Values


- Hope
- Equality/Equity
- Mutuality
- Empathy
- Choice
- Respect
- Authenticity
- Belonging/Inclusion
- Interdependence/Interconnectedness
- Justice/Human Rights

## Core Lived Experience Principles

- Lived experience as expertise
- Self determination
- Recovery-focused
- Person directed
- Strengths based
- Relational
- Trauma informed
- Humanistic
- Voluntary
- Culturally responsive

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<sup>33</sup> Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., Darwin, L., Castles, C., Craze, L., Saunders, M. 2021, National Lived Experience Workforce Guidelines, National Mental Health Commission.



The following tables articulate how lived experience values and principles, ethic and positionality can be embedded in governance and decision-making processes. This includes in service planning, design and delivery, accountability mechanisms, strategic direction and oversight, risk management and monitoring, performance measurement and delegation of authority. These are listed alongside the statements found in the National Lived experience (Peer) Workforce Development Guidelines<sup>34</sup> as they relate to the workforce.



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Every part of the work that we do needs to be laid upon the principles of consumer work, self-determination. It is anti-oppressive. It is non-violent. It is transparent. Transparency is so f\*#king important. So, if we've got a governance framework - whether its financial risk, clinical, corporate, that has those principles within in, then we're going to be way better off. We're going to be able to make decisions that actually support people to grow and develop.

Interview  
Participant

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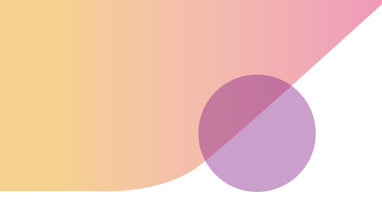
<sup>34</sup> Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., Darwin, L., Castles, C., Craze, L., Saunders, M. 2021, National Lived Experience Workforce Guidelines, National Mental Health Commission.

## Values

Value	What it Means for the Workforce <sup>35</sup>	What it Means for Governance
Hope	Belief in people's fundamental capacity to overcome challenges.	Embedding belief in people's fundamental capacity to know what is right for them and to overcome challenges in systems, structures, policies, processes, practices, programs and services.
Equality/ Equity	Working from a place of common humanity and vulnerability. Actively working to minimise power imbalances.	Ensuring diverse representation and equitable power distribution.  Articulating who is making decisions and where power and authority sits.  Embedding transparent ways of working towards equity of access, equity of experience, equity of investment, and equity of outcomes.
Mutuality	Being in a relationship with another person where both people learn, grow and are challenged through the relationship. Sharing responsibility in relationships.	Building capability and capacity so that people are challenged to learn and grow from each other.  Organisational cultures value different ways of working, knowledge and expertise.
Empathy	Understanding another's experience from a point of common experience and genuine connection.	Promoting shared understanding of the impact of governance structures on people's experiences and using this to inform how future organisational decisions are made and actioned.
Choice	Acknowledging and respecting each person's choices, dignity of risk and boundaries. Acknowledging that the person is the expert of their own experience.	Ensuring systems, structures, policies, processes, practices, programs and services centre the rights of people to make informed choices and enable dignity of risk.  Establishing processes that recognise people are experts of their own experiences and are supported to use this expertise.
Respect	Honouring another's view and experience without judgement or making assumptions.	Setting an organisational culture that embraces others' experiences and promotes non-intrusive curiosity as opposed to judgement or assumptions.
Authenticity	Integrity, being open, honest, trustworthy, and transparent in work practices and relationships.  Valuing the use of lived experience and vulnerability in the service of others transforms these from what may have been perceived as weaknesses into strengths.	Maintaining and following through on commitments made by leadership.  Establishing organisational governance and decision-making processes that facilitate trust, foster accountability and demonstrate integrity and an openness to learning and continuous improvement.  Systems, structures, policies, processes, practices, programs and services adopt strengths-based rather than deficit-based approaches.

<sup>35</sup> Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., Darwin, L., Castles, C., Craze, L., Saunders, M. 2021, National Lived Experience Workforce Guidelines, National Mental Health Commission.





## Value

## What it Means for the Workforce<sup>35</sup>

## What it Means for Governance

<p>Belonging/ Inclusion</p>	<p>Respecting and understanding the value of inclusion and the impact of exclusion. Recognising intersectionality and valuing diversity culture, spirituality, membership in chosen groups and community.</p>	<p>Prioritising spaces in governance and leadership for people from marginalised groups and those we hear from less.</p> <p>Ensuring recognition of intersectionality and valuing diversity of culture, spirituality and membership of chosen identities, groups and communities.</p>
<p>Interdependence/ Interconnectedness</p>	<p>Recognition that we exist in relationships and that the relationships with families and/or social networks are often impactful in our lives and important to healing.</p>	<p>Recognising the broad range of interconnected relationships and networks that assist in growth and healing.</p> <p>Clear processes exist to ensure authentic partnership, connection, and collaboration across teams, services and sectors and with the broader community.</p>
<p>Justice/ Human Rights</p>	<p>Understanding the impact of social justice/inequity on identity and opportunity e.g. race, culture, sexual orientation. Recognising that equal access to resources and support is an important factor in everyone's recovery and healing. Recognising the consumer movement as a response to the history of social injustice and discrimination towards people with lived experience. Recognising how lived experience work is connected to the human rights movement and upholding the human rights of people with lived experience.</p>	<p>Ensuring leadership accountability for embedding and modelling commitment to social justice and human rights.</p> <p>Ensuring a restorative, just and accountable organisational culture and alignment with historic and ongoing aims of the consumer movement.</p> <p>Demonstrating understanding of the impact of social justice/inequity on identity, opportunity and outcome (e.g. race, culture, sexual orientation). Equitable access to resources, support and involvement and leadership opportunities are prioritised as an important factor in everyone's recovery and healing.</p> <p>Acknowledging that the lived experience movement is a response to the history of harm, social injustice and discrimination towards people with lived experience.</p>

## Principles

Principle	What it Means for the Workforce <sup>36</sup>	What it Means for Governance
Lived experience as expertise	The expertise that arises from a lived experience is of equal value to other types of expertise, including academic qualifications.	Embedding lived experience involvement, expertise and leadership at all levels of organisations and across systems.  Systems reflect that trust in and responsibility of lived experience staff and lived experience-led initiatives is equal to the trust and responsibility provided to clinical staff and clinical programs.
Self-determination	Respecting individual choice and personal agency.	Embedding processes that ensure people have the unassailable right to choice, self-agency and dignity of risk.
Recovery-focused	Recognises that individuals can define what recovery/healing means to them, and each person can create a life that is meaningful for them. Interactions are underpinned by hope.	Enabling people involved with or being supported by the system, structure, policy, process, practice, program or service to define recovery and healing, and measuring the success and outcome based on these.
Person-directed	Service access and individual recovery planning/journey is directed by the person themselves and recognises the person as the expert of their own experiences. Respects where each individual happens to be in their journey of recovery/healing, and recognises that goals, values, spirituality, beliefs, and choices will be unique to each person.	Creating person-directed and -led organisational cultures, systems, structures, policies, processes, practices, programs and services that recognise and celebrate people's individuality and unique expertise, values, culture, spirituality, choices and beliefs. Ensuring that these factors are centred to create experiences that support people and promote their recovery.
Strengths-based	Identifying and drawing on existing strengths to support growth, recovery and healing. Recognising the value/learning that can come from experiences of crisis.	Ensuring organisational governance and decision-making processes are based on strengths, growth capabilities and success rather than centring on risk and deficit.
Relational	Relationships are the basis of practice, and connection is used to build relationships of trust. Recognises relationships built on trust and respect as foundational to working effectively with other lived experience workers and within multi-disciplinary environments.	Embedding recognition that authentic mutual relationships enhance trust, healing and impact.  Facilitating relationships that promote continuity of care and opportunities to work in true partnership with people with lived experience at all levels, across systems and in a multitude of ways.  Ensuring experiences are respectful and relational rather than transactional.

<sup>36</sup> Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., Darwin, L., Castles, C., Craze, L., Saunders, M. 2021, National Lived Experience Workforce Guidelines, National Mental Health Commission.



## Principle

## What it Means for the Workforce<sup>36</sup>

## What it Means for Governance

<p>Trauma-informed</p>	<p>Acknowledges the impact and prevalence of trauma, negative experiences and loss of control and power. Emphasises the need for physical, psychological, and emotional safety. Creates opportunities for empowerment and for people to take an active role in their own healing/ recovery. This is also captured in the lived experience conviction that it is better to ask</p> <p>“What happened to you?” not “What is wrong with you?”</p>	<p>Accounting for trauma and previous experiences of harm or loss of control and power by ensuring that systems, structures, policies, practices, processes, programs, services and interactions are person-directed and able to be negotiated and adapted to the needs and preferences of people interacting with or being supported by them.<sup>37</sup></p> <p>Supporting people in ways that enable them to be involved and lead in ways that they choose.</p>
<p>Humanistic</p>	<p>The relational nature of lived experience work is recognised for its effectiveness to engage people through human connection and a holistic focus.</p>	<p>Recognising and creating an organisational culture that supports human connection and holistic understanding of people through decision-making systems, structures, policies, processes, practices, programs and services.</p>
<p>Voluntary</p>	<p>Participation is always voluntary (not coercive) and lived experience workers often take an active role in working towards eliminating forced treatment and restrictive practice.</p>	<p>Ensuring service use and involvement is voluntary and free of coercion and threat.</p> <p>Creating an organisational culture of reflection, responsiveness, evidence gathering and accountability to people with lived experience to eliminate coercion, restrictive practice or other involuntary involvement.</p>
<p>Culturally responsive</p>		<p>Acknowledges the centrality of culture and how that shapes each individual, their worldviews, values, beliefs, attitudes, and interactions with others... requires strengths-based approaches and recognises that if culture is not factored into health care and treatment, the quality and probable impact of that care and treatment is likely to be diminished.<sup>38</sup></p> <p>Recognising and creating organisational systems and processes that encourage people to learn from, respond to and relate respectfully with people of one’s own culture and those from other cultures.</p> <p>Respecting and including Aboriginal and Torres Strait Islander domains of social, emotional and cultural wellbeing.</p>

<sup>37</sup> Reynolds, V. 2012, An ethical stance for justice-doing in community work and therapy journal of systemic therapies, vol. 31, no. 4, pp. 18–33.

<sup>38</sup> Indigenous Allied Health Australia (2019) Cultural Responsiveness in Action: An IAHA Framework [https://iaha.com.au/wp-content/uploads/2020/08/IAHA\\_Cultural-Responsiveness\\_2019\\_FINAL\\_V5.pdf](https://iaha.com.au/wp-content/uploads/2020/08/IAHA_Cultural-Responsiveness_2019_FINAL_V5.pdf)



## Restorative, just and accountable organisational cultures

People have been harmed and traumatised by the organisational culture and practices of mental health services and systems, contributing to fear and stigma and limiting people's future help seeking and available supports.

To transform organisational cultures and outcomes, governance processes and structures must embrace restorative, just cultures instead of those based on avoiding and mitigating risk or laying blame. This must be embedded across all domains of lived experience governance.

Restorative, just and accountable organisational cultures are adaptive, accountable and support lived experience involvement, expertise and leadership at all levels.

Across all domains, consideration must be given to achieving<sup>39</sup>:

- *Moral engagement* whereby people accept responsibility and pursue 'the right thing to do'
- *Emotional healing* as a basis for repairing relationships and trust
- *Reintegration* of the workforce following an incident
- *Addressing the causes* of harm by fixing them.

Restorative, just and accountable cultures create services, organisations, workplaces, cultures and structures that are reflective, fair and open to understanding and being responsive to diverse and inter-sectional experiences. This includes experiences where a service, program, environment, organisational culture, and/or structure has created harm and/or been unhelpful. Within restorative, just and accountable organisational cultures and practice these harms are acknowledged and any factors which caused or contributed towards them are addressed. Whilst individuals should not be held accountable for system failures, they should be for poor performance, not prioritising the rights, needs, preferences, autonomy and decision-making power of people interacting with or being supported by services and organisations, operating outside their scope of professional practice or for misconduct and negligence.



*It's about a truth telling, a reckoning in those places that thought they had it right.  
But they never really asked the person, what it was that they needed.*

Interview  
Participant

Adaptive governance structures facilitate organisational cultures that innovate and are responsive to complexity. Integrating accountability with restorative just approaches across culture, leadership and practice, creates an environment in which changes identified can be accepted and implemented through taking responsibility for ones actions and supported decision-making. It encourages proactive approaches in which adaptations are made when the potential for physical and/or psychological harm is forecast or identified, as opposed to only after harm has occurred.

There can be a tendency to approach risk from a deficit perspective, assuming a defensive position rather than a strengths-based and person-centred approach. At an organisational level, restorative, just

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<sup>39</sup> Decker, S. 2019, Restorative Just Culture Checklist, accessed at <https://www.pslhub.org/learn/patient-engagement/harmed-care-patient-pathways-post-incident-pathways/sidney-dekkers-restorative-just-culture-checklist-r35/>



and accountable organisational cultures counter concerns that clinical governance commonly holds toward risk by seeing risk not as an opportunity for blame, but an opportunity for agency, learning, growth and reconciliation.

Whilst restorative, just and accountable organisational cultures speak to what organisations and systems need, it doesn't negate the need for people interacting with or being supported by systems, structures, policies, processes, practices, programs and services to have access to other pathways to redress and justice. Particularly when they have experienced harm or human rights breaches<sup>40</sup>. Restorative, just and accountable organisational cultures are more nuanced in contexts where risk tolerance is low or where more restrictions are in place, with a need for greater safeguarding and attention to human rights. It must ensure the person, their rights, needs and preferences are centred and promoted as most important.

Such organisational cultures and structures move beyond individuals and invite diverse voices and perspectives, to address the cause of harm with accountability that is forward-looking and solution-focused rather than focused on blame. This considers and addresses the impact of not being helped that may also be harmful.

Restorative, just and accountable organisational cultures move structures and organisations toward acknowledging complexity and operating proactively<sup>41</sup>. Built upon shared accountability and learning, these mindsets and practices allow people to become more involved, to speak up and to become part of the solution which is the landscape of lived experience governance and transformative systems change by, for and with them.

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<sup>40</sup> Katterl, S. 2022, Preventing and responding to harm: Restorative and responsive mental health regulation in Victoria. Australian Journal of Social Issues.

<sup>41</sup> Turner, K., Stapelberg, N.J., Svetcic, J., Dekker, S.W. 2020, Inconvenient truths in suicide prevention: Why a Restorative Just Culture should be implemented alongside a Zero Suicide Framework, Australian & New Zealand Journal of Psychiatry. 54(6):571-581. doi:10.1177/0004867420918659.

## Domains of Lived Experience Governance



### Domain 1: Partnership And Co-Production

Partnership and co-production by, with and for people with lived experience must be amplified and embedded across all levels of governance and practice to inform decision-making and drive local solutions.

Authentic partnership involves building an ongoing open two-way dialogue whereby both parties are able to initiate conversation and action and share power and decision-making together.

Co-production<sup>42</sup> and other participatory methodologies seek to address power differentials within systems. Their success require those with more power to surrender power so they can share it with those who have traditionally had less access to it and create empowering environments for and with others. It demands the inclusion of the most relevant forms of lived experience expertise from the outset through every step, including articulation of problems, clarification of priorities, co-design and implementation of solutions and evaluation of effectiveness. Co-producing solutions by, with and for our most vulnerable people and communities benefits all Australians.

Authentic and reciprocal partnerships that negotiate safety enhance involvement experiences and outcomes. They also reduce the chance of people experiencing re-traumatisation. *'Structuring Safety describes the practices of negotiating or co-constructing conditions, structures, and agreements that will make space for 'safe-enough' work'*<sup>43</sup>. Adopting a stance of safe-enough partnership and practice recognises that no single person, policy or program can guarantee a felt sense of safety for or with others. It is imperative that individuals, programs, services and organisations do all in their power to reduce the potential for harm by not replicating oppression or ignoring facets of self and experience important to those they are in relationship with.

This responsibility for authentic partnership and co-production includes a commitment to calling out racism and negotiating cultural safety and empowerment, creating *'an environment that is spiritually, socially and emotionally safe, as well as physically safe for people'*<sup>44</sup>.



*Good partnership practice would see you sort of sharing power, both having mutual obligations and commitments to a particular project, having shared and equal decision-making responsibilities.*

Aboriginal  
Interview  
Participant

<sup>42</sup> Roper, C., Grey, F., Cadogan, E. 2018. Co-production - Putting principles into practice in mental health contexts, The University of Melbourne, accessed at [https://healthsciences.unimelb.edu.au/\\_\\_data/assets/pdf\\_file/0007/3392215/Coproduction\\_putting-principles-into-practice.pdf](https://healthsciences.unimelb.edu.au/__data/assets/pdf_file/0007/3392215/Coproduction_putting-principles-into-practice.pdf)

<sup>43</sup> Reynolds, V. 2012, An ethical stance for justice-doing in community work and therapy, journal of systemic therapies, vol. 31, no. 4, pp. 18-33

<sup>44</sup> Williams, R. 1999, Cultural safety – what does it mean for our work practice?, Australian and New Zealand journal of public health, vol. 23 no. 2, pp. 213-214.

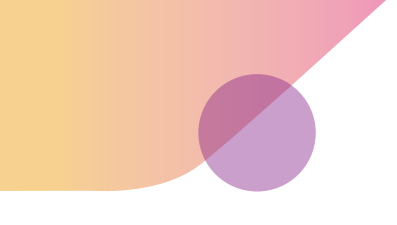


## What will be experienced and seen in governance systems and processes:

- *Prioritised and Embedded* – Strategic directions and priorities embed centring and amplifying the perspectives, voices and contributions of people with lived experience in the co-production of systems, structures, policies, processes, practices, programs and services.
- *Adequate Resourcing* – Adequate resourcing for partnership and co-production, including making sense of issues and possible solutions together and co-commissioning to allow for (re)design, transformation and continuous improvement informed by participatory and inclusive methodologies.
- *Two-way Communication Pathways* – Open, visible and two-way communication pathways between people with different roles, knowledge, expertise, responsibility and authority support and enable partnership, co-planning, co-design, co-delivery/implementation and co-evaluation of systems, structures, policies, processes, practices, programs and services.
- *Relational not Transactional* – Systems, structures, policies, processes, practices, programs and services embed relational rather than transactional interactions and methods. Meaningful connections that are authentic, inclusive, culturally responsive, mutually beneficial, structure safety and are nurtured over time are prioritised.
- *Person-Defined Impacts* - People interacting with or being supported by an organisation have opportunities to determine the value and impact of initiatives and this information is used as a measure of safety, quality and outcomes for evaluation, reporting and funding purposes.
- *Lived Experience-Initiated Opportunities* - Mechanisms are available for lived experience-initiated partnership and co-production opportunities that involves both new and frequent contributors with a range of different experiences and relationships to the organisation, program or service.
- *Co-produced Performance Measures* - Commissioning processes and reporting examine performance against system-wide co-created quality measures for partnership and co-production activity, outputs and outcomes.

## This means that...

- People with lived experience, including the lived experience (peer) workforces, feel heard, valued, supported, and their roles are understood and able to be leveraged within and across systems, structures, policies, processes, practices, programs and services.
- People with lived experience have real decision-making influence through access to opportunities to strengthen capacity, skills, experience and confidence. They are able to exercise their power and see the results of that.
- Lived experience expertise is approached with openness and willingness to strengthen understanding of people's experiences, rights, needs and preferences as a step towards forming trusting partnerships that benefit all.
- Partnerships operate in an inclusive, safe and responsive way, ensuring that people with the most relevant forms of lived experience are influencing and co-producing systems, structures, policies, processes, practices, programs and services to meet their needs.

- 
- People with diverse and intersectional experiences, particularly Aboriginal and Torres Strait Islander peoples, are able to influence and co-produce programs to meet their needs and experience environments that are culturally, spiritually, physically, emotionally and socially safe.
  - When partnering with Aboriginal and Torres Strait Islander peoples, co-production honours and preferences their ways of knowing, being and doing.
  - People are trusted to have capacity to understand, make and act upon decisions alongside efforts to honour, support and strengthen this capacity at all levels of governance and systems, structures, policies, processes, practices, programs and services.
  - There are meaningful opportunities to receive, provide, deny and remove consent provided for any and all aspects of treatment and involvement in partnership activities without fear of restraint, retaliation, coercion, discrimination or reputational damage. Relevant details and alternatives are thoroughly and meaningfully explained with a communication style appropriate for relevant parties.
  - Formalised partnerships are in place between people and organisations across relevant interest areas with active communication, collaboration and contribution to allow for representation of their rights, needs, preferences, autonomy, decision-making power and priorities.
  - Partnerships are sustained through regular networking opportunities between local people, groups and organisations without the express purpose of contributing to any one specific policy, program or service initiative.
  - Program commissioning and funding is dependant and evaluated on an ability to centre partnership and co-production approaches. This includes adequate resourcing for these methods and the appropriate remuneration of people with lived experience and relevant representatives, including organisations, where this may not be part of their core business, role or function.
  - Evaluation is based upon measures of success defined and agreed upon by the people interacting with or being supported by the systems, structures, policies, processes, practices, programs and services rather than externally determined measures derived without input of people with lived experience.





## Domain 2: Safeguarding, Responsibility and Power

Safeguarding led by, for and with people with lived experience proactively shifts policies, workforces and systems towards safety practices that are grounded in and responsive to people and their rights, rather than a prioritisation of process, risk-mitigation or fears of the system and people within it<sup>45</sup>

Such shifts enable a lens of Responsibility To - and not For or Over<sup>46</sup> and dignity of risk to be embedded and realised, where the personal growth and quality of life of people is enhanced through the dignity afforded by risk-taking<sup>47</sup>. Exercising self-agency, and learning from experiences both positive and negative, can benefit recovery, healing and outcomes whilst also providing avenues for alternative and innovative responses to distress to be explored and benefited from.

It is the responsibility of organisations and those with power to create, adapt and embed safe-enough environments and cultures. This includes clear recognition and acknowledgement of, and structures in place to eliminate, impacts associated with policies, practices and services that have been harmful or unhelpful for people.

Settings that successfully navigate these tensions adopt a different relationship to risk and risk tolerance and engage in robust governance and decision-making processes that are about maintaining safety of, and decision-making power with, the person for as long as possible rather than mitigating risk and removing the person's power to decide too soon.



*It's a responsibility to, not a responsibility for. So that's bringing in a power dynamic sort of element to it. It's, at its heart, it's respectful and humanistic so it's really drilling down as far as you can. What do we mean by that? It takes into account people as a whole. And it's respectful of all of those parts of themselves. And that is, I think, one of the most common core things that is necessary here.*

Interview  
Participant

Governance structures and processes aligned with this articulate practices and pathways that support person-centred and -led decision-making across the support and service continuum, with careful consideration for the points of interaction, care and governance when a person's rights and preferences are more likely to be removed. In addition, there are clear parameters, expectations and workforce capability requirements established to ensure legal and professional responsibilities align with legislation and contemporary practice informed by lived experience expertise rather than assumed ideas held about duty of care and mandatory reporting obligations. A central underpinning tenet of this is acceptance that people interacting with or being supported by services and organisations, and to a lesser degree their communities, carers, families, kin and supporters of choice, have responsibility to and hold risk over their recovery and lives before, within and outside of contact with professionals and service systems.

<sup>45</sup> White, R. 2022, Reimagining Safety Beyond Safeguarding, Blog Posted on 4 July 2022, accessed at <https://www.nsun.org.uk/reimagining-safety-beyond-safeguarding/>

<sup>46</sup> Western Mass RLC, 2020, Alternatives to Suicide Groups Charter, August 2020: [info@westernmassrlc.org](mailto:info@westernmassrlc.org)

<sup>47</sup> Ibrahim, J., & Davis, M. 2013, Impediments to applying the 'dignity of Risk' principle in residential aged care services Australian Journal of Aging, 1-6.



*Allowing people to make choices. ... And make choices implies that there's some dignity of risk there. ... It's about choice and managing responding to people in a compassionate way. And thinking about risk differently, not in a controlling way.*

Interview  
Participant

Power imbalance must be made explicit and addressed to recentralise power and achieve equity, enabling people to have their needs fully heard, understood and met at individual and community levels. Addressing such power imbalances through centring values of equality, freedom, co-operation and respect for everyone's needs, often seen in and advocated for by Aboriginal and Torres Strait Islander and other diverse or marginalised communities, creates opportunity for previously unheard voices to be identified, amplified and prioritised.

Power is realised through the exercising of it – if not developed, witnessed or actioned, the potential for power to shape decision-making is reduced.

Equitable, consensus-based and supported decision-making approaches that are person-directed and -led dismantle hierarchy, redistribute power and value, amplify, prioritise and honour lived experience. These and community insights and contributions need to be evident across governance systems, structures, policies, and practice.

Ensuring lived experience involvement opportunities, expertise, leadership and lived experience (peer) workforces are embedded and accessible to people strengthens safeguarding and justice-based practices, including choice and control remaining with people for longer. Having high quality, psychologically safe and validating supports during crisis or distress will transform a person's experience of distress, as well as remove the hardships of having to navigate care contexts and assessments that may not be trauma informed or perceived as threatening.

### What will be experienced and seen in governance systems and processes:

- *Rights are Upheld* – Rights of people interacting with or being supported by systems, structures, policies, processes, practices, programs and services are known, understood, promoted and upheld. People are able to openly express themselves, their hopes, needs and preferences without fear of force, coercion, restriction or detainment.
- *Dignity of Risk* - People holding power and responsibility over their own experiences and lives, which may include making less than ideal or recommended choices, is accepted as providing the best approach for recovery, healing and growth to be fostered rather than a potential risk that must be managed.
- *Responsibility To, Not For or Over* – Systems, structures, policies, processes, practices, programs and services centre and demonstrate a 'responsible to people' framing and ethic that is inclusive of an actioned commitment to eliminate coercive and restrictive practices.
- *Decision-Making Transparency* – There is transparency and clear articulation of who has the ability to make particular decisions, as well as why and how those parameters have been set. Opportunities are provided for people to progressively influence decisions at different levels within and across systems, structures, policies, processes, practices, programs and services.

- *Redistribution of Power* – Systems, structures, policies, processes, practices, programs and services actively work towards equitable distribution and sharing of power with those most impacted by the issue or decision being made and with consideration for the layers of diverse and intersectional experiences they may have. This includes improved understanding of different levels of access to power, impact on people’s experience and a redistribution of power from those that have traditionally held it.
- *Capacity to Exercise Power* - People with lived experience are able to develop and exercise their own power to be better equipped to influence and make decisions, as well as see the result of their input.
- *Measures that Matter* - Visible and highly valued measures and targets regarding people’s experiences of safety, autonomy and justice are benchmarked and reported.

### This means that..

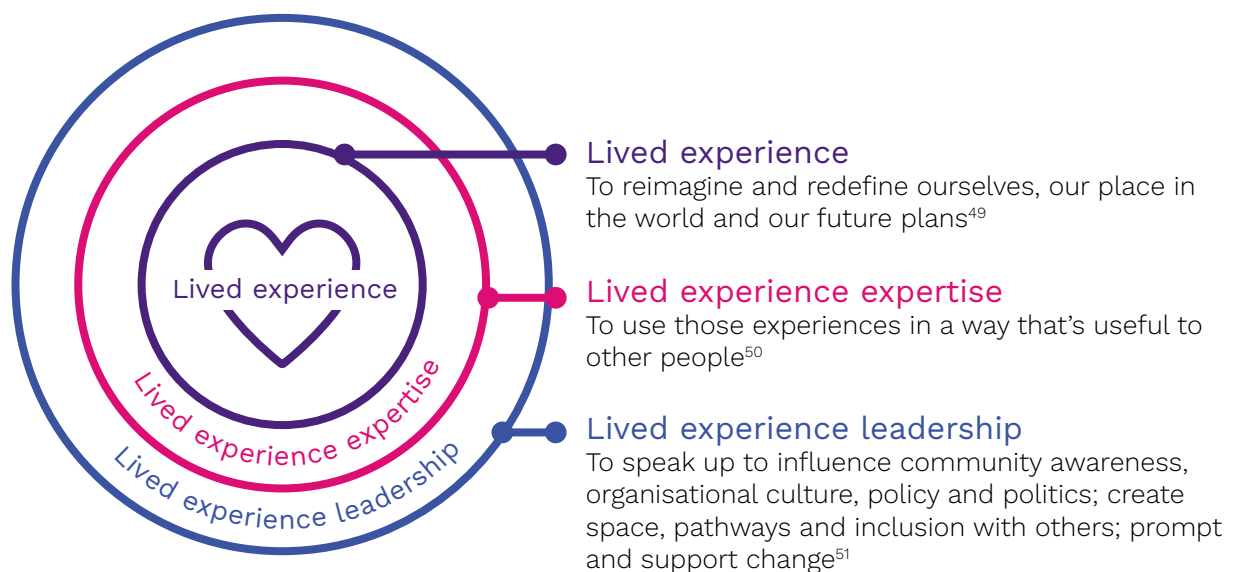
- Organisations have a commitment towards strength-based approaches and enable people to exercise their autonomy and power.
- All decisions and actions centre and affirm human rights, dignity, choice and control.
- There is proactive education and strict adherence to, championing of and commitment to embed the rights of people at all levels of interaction and decision-making.
- People feel respected, valued and empowered. They see themselves, their rights, needs and preferences represented in the systems, structures, policies, processes, practices, programs and services.
- Aboriginal and Torres Strait Islander peoples have access to and exercise power to define their individual and communities’ experience, needs and preferences, and this is reflected in systems, structures, policies, processes, practices, programs and services.
- Supported decision-making is given primacy. People’s ability to make decisions and have these decisions respected, without use of manipulation or force, are documented and enabled by systems, structures, policies, processes, practices, programs and services.
- People are supported to exert their autonomy and dignity of risk is embraced through a harm minimisation lens so that agency, empowerment and self-determination are fostered.
- Organisations and governance bodies demonstrate that lived experience expertise is valued and holds weight against other evidence and knowledge bases, information and power is shared, and people’s voices are heard and influence decision-making.
- Pathways to access different levels of decision-making power within systems, structures, policies, processes, practices, programs and services are visible , maintained and protected. People who access these pathways are supported to build capability and capacity and not have their dignity, rights or expertise undermined.
- People with lived experience and those that interact with or are supported by systems, structures, policies, processes, practices, programs and services are embedded in existing safeguarding processes, such as complaints pathways, accreditation audits and so on.
- Governance and commissioning bodies adopt ‘Safeguarding, Responsibility and Power’ principles and actions, and ensure accountability mechanisms are part of commissioning, funding and reporting processes.



### Domain 3: Lived Experience Involvement, Expertise and Leadership

The unique perspectives and contributions that lived experience involvement, expertise and leadership brings must be recognised and acknowledged within and across the health and social sectors and embedded within all governance systems, structures, policies, processes, practices, programs and services. Approaches underpinned and aligned with the ideal of epistemic equality, where lived experience knowledge is accepted as equally relevant and important as other knowledge, best enable this.

Lived experience perspectives emerge from universal experiences such as loss of power, relationships marginalisation, safety, employment, status, citizenship and home.<sup>48</sup> Drawing on this for the benefit of others requires expertise and leadership and is a technical skillset in its own right.



To enable lived experience involvement, expertise and leadership to thrive, organisations and boards must go beyond inviting people with lived experience to merely share experiences and reflections. They must be willing to recognise the expertise and additional skillsets and qualifications that people using their lived experience for change hold, and share power and provide real opportunities for people with lived experience to influence outcomes and decisions.

They have an obligation to, enable lived experience leaders to support and mentor other members of the lived experience (peer) workforces and shape decision-making pathways for how people interacting with or being supported by systems, structures, policies, processes, practices, programs and services are partnered with and responded to. This includes co-producing decision-making guidelines that are completely person- and peer-led, where contexts and parameters for the scope of this are clearly articulated, advocated for and resourced to succeed.

<sup>48</sup> Byrne, L., & Wykes, T., 2020 A role for lived experience mental health leadership in the age of Covid-19, *Journal of Mental Health*, 29:3, 243-246, DOI: 10.1080/09638237.2020.1766002

<sup>49</sup> *ibid.*

<sup>50</sup> *ibid.*

<sup>51</sup> Loughhead, M., Hodges, E., McIntyre, H. & Procter, NG. (2021). A roadmap for strengthening lived experience leadership for transformative systems change in South Australia. LELAN and UniSA, Adelaide. [www.lelan.org.au/wp-content/uploads/2021/08/ALEL\\_digital\\_linked.pdf](http://www.lelan.org.au/wp-content/uploads/2021/08/ALEL_digital_linked.pdf)



*It's not just getting a seat at the table. It's about redesigning the table, and who says we need a table anyway. It's about taking the wisdom from the people who've lived life to the edge and shaping the way life could be for everybody, not to reduce risk or reduce harm, but to improve quality.*

Interview  
Participant

Whilst some clinicians and other professionals may have their own lived experience, and may have chosen to pursue a particular career or work role because of it, it does not mean and cannot be assumed that their experiences influence their practice or decision-making or that they are knowledgeable of, or aligned with, the values and principles of the broader lived experience movement. It is imperative that the experiences and contributions of other leaders and professionals with lived experience, 'leaders with lived experience', are valued though not equated as the same as that of 'lived experience leaders'.

To reduce this potential erasure of the unique skillset, responsibility, emotional labour and connection to the collective experiences of people with lived experience that lived experience leaders have, designated roles with titles that accurately convey their decision-making responsibilities, capacity and expertise are necessary.




*We can't start to address the issues of power if we are not in the places where power is exerted. And governance spaces are the epitome of those spaces.*

Interview  
Participant

### What will be experienced and seen in governance systems and processes:

- *Strategic Recognition and Action* - Strategic direction ensures lived experience expertise and leadership is recognised as a vital form of expertise and is sought out in planning, design, implementation, evaluation, governance and decision-making processes, across a range of roles and systems, structures, policies, processes, practices, programs and services.
- *Opportunities and Integration* - Lived experience involvement, expertise and leadership are embraced. This includes opportunities for capacity building, role progression and full integration of people with lived experience across systems, structures, policies, processes, practices, programs and services.
- *All Levels, in Diverse Roles* - Lived experience leaders hold a diversity of roles across the decision-making hierarchy and have equivalent decision-making authority, recognition and remuneration to those within non-lived experience roles at the same level.
- *Presence and Authority* - Human and other resourcing ensures there is a notable presence of lived experience leaders with decision-making authority at leadership and governance levels within systems, structures, policies, processes, practices, programs and services, including in commissioning and funding. This includes robust policies and procedures to define role, responsibility, scope of practice and organisational commitment to employee social and emotional wellbeing for all people.
- *Resourced to Leverage* - People with lived experience are resourced and supported to leverage their lived experience as expertise in personal, professional and socio-political spaces, including as leaders across systems or sectors they intersect with where they are not bound or limited by their role or jurisdiction.

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- *Lived Experience-led Change* – Lived experience-led spaces are created that enable lived experience leaders to authentically create and lead change within, across and beyond systems, structures, policies, processes, practices, programs and services.
  - *Critical Reflection* – People with lived experience in non-designated roles are supported to reflect on how they make sense of and may draw on their experiences. This requires clear recognition of the difference between having lived experience and the contrast of being employed primarily for one's lived experience expertise and the unique skillset and practice experience required to show up, centre and continue to live it within designated roles.

### This means that...

- Lived experience expertise is recognised as a form of knowledge and evidence in its own right and stands equally alongside other expertise and ways of knowing.
- Organisations and boards share power and provide real opportunities for people with lived experience, their expertise and leadership to influence decisions and outcomes.
- There is ongoing investment into development of workplace supports and career pathways for lived experience (peer) workforces to ensure they remain viable, sustainable and effective.
- Lived experience expertise appropriate to the role held by, or within the scope of practice of, the lived experience (peer) workforces, is easily accessed.
- The unique intersectional lived experience expertise and leadership of Aboriginal and Torres Strait Islander peoples and other diverse and marginalised groups is valued, sought and embedded within governance and systems, structures, policies, processes, practices, programs and services, including through designated cultural peer roles.
- People in designated lived experience roles are actively supported to develop their capability and capacity to lead and have influence at all levels of organisations, governance and system change endeavours.
- There is a meaningful prevalence of lived experience designated roles with decision-making authority that allows for advocacy, change and innovation to be spearheaded by lived experience leaders.
- There is increased development, resourcing, implementation and visibility of lived experience-led initiatives across systems, structures, policies, processes, practices, programs and services.
- Lived experience leaders in governance and decision-making roles is strengthened by policy and seen as a requirement by commissioning, funding and accreditation bodies.



## Domain 4: Transformative Workforces and Practice

System transformation requires collaborative effort and shared vision.

Governance systems, policies and practice must build and strengthen capability and capacity of: the lived experience (peer) workforces to participate as an essential part of the way all mental health services are delivered; and the broader workforce to understand and amplify the vital role, scope, and contributions of lived experience (peer) workforces to the mental health and other systems.

All workforces including people without lived experience, or those with lived experience in non-designated roles, have a responsibility for embedding and upholding the values, principles and model of lived experience governance. This includes an ongoing commitment to building workforce practices and capabilities to address racism, exclusion, injustice and discrimination and drive culturally responsive action and transformation, at personal, organisational and system levels.

Improved role clarity, systemic support and understanding around lived experience and associated work, positively impacts on the capacity and capability of workforces to collaborate for transformative systems change.

Transformative workforces are holistic, integrated and inter-disciplinary, where the unique attributes and contributions of each workforce along the care and decision-making continuum are valued, and their collective impact facilitates change and strengthens outcomes. This collaborative approach needs to extend past support and guidance offered to people interacting with or being supported by them. It must enable openness with people across organisational and structural hierarchies to allow for exploration, questioning and challenging of current practice so that workforces can be continually transform practice and the mark they leave on the world.



*There's always that undercurrent of who's more important than the other, where it should be. We should try and think about who brings what skill, at what time in the best way, because everyone at some sort of along the trajectory of care everyone has their place.*

Interview Participant

### What will be experienced and seen in governance systems and processes:


- *Person-directed and -led* - Workforces actively centre, prioritise and respond to the rights, needs and preferences of people interacting with or being supported by systems, structures, policies, processes, practices, programs and services, as well as their carers, family, kin, other supporters of choice and communities.
- *Organisational Commitment to Adopt and Align* - Commitment to align systems, structures, policies, processes, practices, programs and services with implementation of The National Lived Experience (Peer) Workforce Development Guidelines and National Mental Health Workforce Strategy (once finalised).

- *Shared Understanding* - Interprofessional collaboration, communication and ongoing education and professional development opportunities for all workforces ensure understanding and utilisation of the different skills, expertise, knowledge base, values and responsibilities held by the various workforces.
- *Shared Responsibility* - All workforces understand, create space for and enable lived experience to be integrated, utilised and able to have the impact it can.
- *Role Clarity* – Clear scopes of practice, practice frameworks and decision-making guidelines assist with the understanding of role clarity, responsibilities, skills and knowledge base of each workforce to better enable communication, collaboration and practices best aligned with rights-based and person-led approaches.
- *Self-determining* – The lived experience (peer) workforces and people interacting with or being supported by systems, structures, policies, processes, practices, programs and services are self-determining, meaning they have agency, hold power and have capacity to transform governance structures and decision-making processes. There is a clear commitment to and demonstrated allyship for Aboriginal and Torres Strait Islander self-determination.
- *Allyship* – Systems, structures, policies, processes, practices, programs and services support lived experience allyship, whereby people within other workforces, different roles and perspectives draw on, enable and amplify the skills and strengths of people with lived experience, lived experience expertise and leadership.

### This means that...

- People interacting with or being supported by systems, structures, policies, processes, practices, programs and services feel respected, valued and empowered. This is because workforces and practices are safe-enough, inclusive and responsive to individuals, particularly those with intersectional experiences and/or more greatly impacted by past and ongoing marginalisation, discrimination, racism, homophobia, transphobia, ablism and sexism.
- Workforces are committed to ongoing learning to build cultural capabilities and engage in culturally responsive practices that are person-centred and -led.
- Aboriginal and Torres Strait Islander lived experience expertise and leadership within communities and workforces is prioritised in the planning, design, implementation and evaluation of systems, structures, policies, processes, practices, programs and services relevant to them.
- Workforces have understanding of and value the roles, skills and expertise held by other workforces, and actively seek out opportunities to collaborate with and make use of their different knowledge bases, skills, roles and perspectives.
- Workforces operate within their respective scopes of practice, working together and alongside people interacting with or being supported by systems, structures, policies, processes, practices, programs and services to support optimal experiences, decision-making and outcomes.
- Lived experience, clinical and managerial expertise and their practice are aligned to create stronger and more cohesive systems, structures, policies, processes, practices, programs and services.



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- Collaboration between lived experience and other workforces will be commonplace, allowing the clinical and non-clinical workforces to be more integrated, efficient and effective.
  - Commissioning and funding bodies will be able to have confidence in the safety, support and skill level of all workers in the programs and organisations they commission or fund.
  - Leadership and governing bodies will be able to gain a better perspective on the culture, values and strength of the workforce at any time as the workforce is more communicative and collaborative.
  - Broader structures and processes related to human resources, commissioning, insurance, accreditation and so on, account for and enable lived experience governance to exist and thrive.



## Domain 5: Innovation and Continuous Improvement

Services and systems are more likely to achieve maximum effectiveness and efficiency when a systems approach to improvement and people involved with the service or practice co-produce or lead the improvement and innovation processes.

If the aim of innovation and continuous improvement of structures, services and programs is for people to have inclusive, culturally responsive, high quality and safe experiences and achieve the best possible life and health outcomes, then the focus needs to be on long term outcomes rather than managing short term risk.

Co-evaluation processes are needed as a subset of co-production, innovation and continuous improvement efforts and alongside ongoing research into contemporary best practices. This ensures the measures that determine what constitutes innovation or improvement are based upon what matters at that moment in time to the people interacting with or being supported by systems, structures, policies, processes, practices, programs and services.

Strengthening connections people have to the 5 Rs of citizenship<sup>52</sup>: *rights, responsibilities, roles, resources, and relationships that society offers to its members through public and social institutions* will also assist this and create the conditions for rights-based and truly person-directed and -led development. Processes and measures should also be in place to meaningfully communicate progress and impact to people and communities, including Aboriginal and Torres Strait Islander peoples and others who are impacted greatest by past marginalisation, discrimination, racism, homophobia, transphobia, ablism and oppressive practices that continue to exist within systems and have consequences for their lives.



*We need to have a new way of working, where we never do a thing without it being supported by some kind of lived experience co-evaluation and continuous improvement process.*


ThinkTank  
Participant

Within the ongoing development of embedding lived experience involvement, expertise and leadership in systems, structures, policies, processes, practices programs and services a parallel development of processes and governance structures to guide systems transformation will be necessary. This may include simultaneous development of a scope of practice and practice framework to govern and review practice. While this creates burden of additional work and has the potential to present unique challenges, this is an opportunity for greater cohesion and alignment of ideal and actual practice standards and workforce capabilities.

Innovation and continuous improvement within the context of lived experience governance includes enabling and promoting adaptation and innovation towards the framework itself, alongside other frameworks, decision-making guidelines and accreditation processes. There is room for evolution of current clinical governance and practice compliance with human rights and other legislation, by ensuring rights are embedded in service planning and evaluation. *Upheld by quality and safety frameworks. Assessable*

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<sup>52</sup> Ponce, A.N., Rowe, M. 2018, Citizenship and Community Mental Health Care, American Journal of Community Psychology: 61(1-2), 22-31. doi:10.1002/ajcp.12218.



using outcome data based on consumer perspectives. Maintained through empowerment and supervision of staff. Entrenched in consumer feedback and oversight mechanisms<sup>53</sup>. It is essential that such values and principle-driven critical lenses are adopted and integrated into all future governance frameworks to prompt ongoing innovation.

### What will be experienced and seen in governance systems and processes:

- *Rights-Based* - The rights, needs and preferences of people interacting with or being supported by systems, structures, policies, processes, practices, programs and services, are continually understood, upheld, represented and strengthened.
- *Person-centred Decision-making* - Governance, commissioning and funding bodies encourage and centre people in decision-making and operational quality improvement processes.
- *Lived Experience-led Change* - Changes to systems, structures, policies, processes, practices, programs and services are informed by and led by people most impacted by them, with consideration for intersectional experiences and understandings.
- *Evidence-Informed Improvement* - Governance bodies regularly invest in research and participatory methodologies that directly involve people with lived experience to identify opportunities and pathways towards improvement.
- *Best Practice Development* – Ongoing investment in training and development to ensure contemporary best practice across workforces is embedded in systems, structures, policies, processes, practices, programs and services.
- *Sustained Investment* - Sustained investment in examining, revising and strengthening decision-making structures, processes and the tools that guide them, including participatory and culturally responsive methodologies.
- *Ongoing Innovation and Improvement* – The Framework will be tested and modified throughout its implementation to ensure that it is appropriate to the setting and context where it is being adopted and continues to be a piece of work which challenges systems, structures, policies, processes, practices, programs and services to better uphold the rights and facilitate the leadership of people with lived experience.

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<sup>53</sup> Katterl, S., & Maylea, C. 2021, Keeping human rights in mind: embedding the Victorian Charter of Human Rights into the public mental health system, *Australian Journal of Human Rights*, 27:1, 58-77, DOI: 10.1080/1323238X.2021.1943300



## This means that...

- Human rights is a non-negotiable consideration within safety, quality, continuous improvement and governance systems and processes.
- People will see the potential for, and be provided with, opportunities to influence and improve systems, structures, policies, processes, practices, programs and services.
- Both bottom-up and top-down change aligned with the rights, needs and preferences of people interacting with, or being supported by systems, structures, policies, processes, practices, programs and services is supported and drawn on to enhance safeguarding and guide quality improvements and innovations.
- Innovation and quality improvement processes are culturally responsive and include Aboriginal and Torres Strait Islander understanding and approaches to social and emotional wellbeing.
- Workforces are provided with opportunities to train, grow and strengthen their practice informed by all forms of evidence, including lived experience.
- Organisations demonstrate how they involve people in their continuous improvement efforts to resolve complaints and feedback.
- Feedback and input are regularly sought from people interacting with, being supported by or delivering on systems, structures, policies, processes, practices, programs and services, including through open processes for complaints and redress.
- Organisations engage in and proactively seek to develop, implement and disseminate process and practice innovations and research.
- Accountability mechanisms and cultures are designed across the system to enable a 'more than compliance approach' with improvement targets that demand more than the minimum and aim for doing the best.

## Lived Experience Governance Roles and Responsibilities

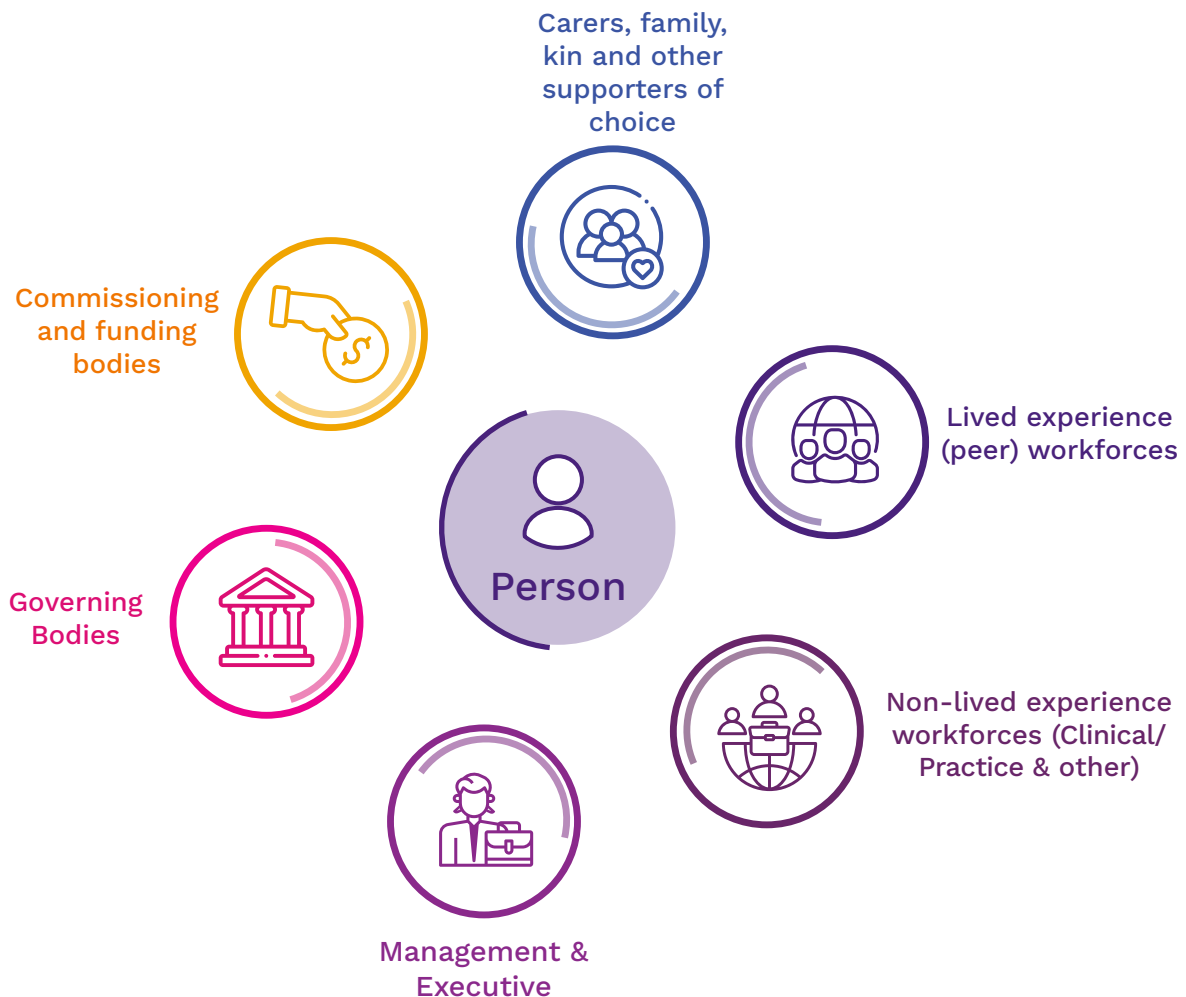
The rights, needs, preferences autonomy and decision-making power of people are at the heart of all aspects of lived experience governance. However, the onus is not always on the person to ensure this occurs. It takes sustained and intentional effort on the part of all key people across systems, structures, policies, processes, programs and services that people interact with or are supported by to ensure this happens in practice.

There are many important roles that contribute to ensuring the promise of lived experience governance is realised, as outlined in the Figure below.



*It's everybody's responsibility, it's not just the people in the lived experience roles. That everyone else plays a systematic role in embedding lived experience leadership, even though they're not employed as a lived experience leader, that's two different things. That's how I see it is enveloping at all, in a sense that, with your clinician or a CEO that isn't in a lived experience, you still have... you arguably have the most responsibility in upholding those principles and values.*

ThinkTank  
Participant





## Person

People interacting with or being supported by systems, structures, policies, processes, practices, programs and services are essential partners in their planning, delivery, and evaluation. They are experts in their own experiences and are best placed to determine the safety and quality of their interaction, and whether their needs and expectations are being met.



## Carers, Family, Kin and Other Supporters of Choice

Whilst it is critical that the rights, needs, preferences, autonomy and decision-making power of the person most impacted by policies and interactions with organisations and care providers is centred, the experiences and contributions of carers, family, kin and other supporters of choice must also be considered. They too have a right to contribute to and be included in the planning, delivery, and evaluation of systems, structures, policies, processes, practices, programs and services.



## Lived Experience (Peer) Workforces

The lived experience (peer) workforces are a unique and separate discipline that offers a valuable contribution to the mental health and social sectors. As its own discipline, lived experience work has distinct values, principles, and theories that define lived experience work and the way it is practised. They use their own lived experience to inform their practice and amplify the voice and contributions of people with lived experience to inform governance processes.



## Non-Lived Experience Workforces (Clinical/Practice and other)

Other workforces involved in governance, policy-making and the delivery of care, programs and services may comprise clinicians, support workers, community workers, policy and program/project managers, human resource staff and other frontline staff. As allies they are essential to ensuring systems, structures, policies, processes, practices, programs and services are person-directed or led and co-produced with people with lived experience.



## Management and Executive

Managers and people in executive roles are responsible for providing leadership to operationalise the strategic direction of an organisation or implementation of policy and practice standards. They also hold responsibility for ensuring operational processes are implemented that support staff to deliver safe, effective and high-quality care, services and programs that centre the rights, needs, preferences, autonomy and decision-making power of people with lived experience, as well as their inclusion in governance and decision-making processes.



## Governing Bodies










Governance bodies such as Boards and Committees of Management have overarching responsibility for the strategic direction of an organisation or entity, including the oversight and monitoring of the quality, safety and effectiveness of their systems, structures, policies, processes, practices, programs and services. As detailed in their constitution, strategic plan or other governing documentation they must ensure the services and programs delivered within the organisation are safe and of high quality, aligning with accreditation standards and legislation where relevant and the rights, needs, preferences, autonomy and decision-making power of people with lived experience.



## Commissioning and Funding Bodies

Commissioning and funding bodies often set the governance parameters, policy framework or standards for the organisations and programs that they fund. They can influence the development and implementation of organisational governance processes and have a responsibility to ensure the rights, needs, preferences, autonomy and decision-making power of people are enabled, as well as their inclusion in governance and decision-making processes. They should also do this within their own systems, structures, policies, processes, practices, programs and services.








## Roles and Responsibilities Across Domains

	 Person	 Carers, family, kin and other supporters of choice	 Lived experience (peer) workforces	 Non-lived experience (peer) workforces	 Management and/or executive	 Governing bodies	 Commissioning and funding bodies
Partnership and Co-Production 	<p>Partnered with to contribute to services that are developed by, for and with people with lived experience.</p> <p>Partner in the co-planning, co-design, co-delivery and co-evaluation of systems, structures, policies, processes, practices, programs and services that affect them.</p>	<p>Contribute to <u>and</u> support the person with lived experience to partner in the co-planning, co-design, co-delivery and co-evaluation of systems, structures, policies, processes, practices, programs and services.</p>	<p>Partner in the co-planning, co-design, co-delivery and co-evaluation of the systems, structures, policies, processes, practices, programs and services that they are part of.</p>	<p>Contribute to <u>and</u> partner with and support people with lived experience to contribute to the co-planning, co-design, co-delivery and co-evaluation of systems, structures, policies, processes, practices, programs and services.</p>	<p>Ensure operational processes support people with lived experience to contribute to the co-planning, co-design, co-delivery and co-evaluation of systems, structures, policies, processes, practices, programs and services.</p>	<p>Oversee the development of strategic priorities that support people with lived experience to contribute to the co-planning, co-design, co-delivery and co-evaluation of systems, structures, policies, processes, practices, programs and services.</p>	<p>Establish and maintain contractual requirements for funding recipients to partner with people with lived experience in the co-planning, co-design, co-delivery and co-evaluation of systems, structures, policies, processes, practices, programs and services.</p>
Safeguarding, Responsibility and Power 	<p>Supported to exercise their agency, autonomy and decision-making power.</p>	<p>Value and support the person with lived experience to exercise their agency, autonomy, decision-making power and contribute as needed.</p> <p>Able to have their own voices heard.</p>	<p>Contribute to decision-making and exercise their own agency and autonomy.</p>	<p>Value and support people with lived experience to exercise their agency, autonomy and decision-making power.</p>	<p>Ensure operational processes value and support people to exercise their agency, autonomy and decision-making power.</p>	<p>Oversee the development of strategic priorities that value and support people to exercise their agency, autonomy and decision-making power.</p>	<p>Establish and maintain contractual requirements for funding recipients that support people to exercise their agency, autonomy and decision-making power.</p>










Lived Experience Involvement, Expertise and Leadership










 Person	 Carers, family, kin and other supporters of choice	 Lived experience (peer) workforces	 Non-lived experience (peer) workforces	 Management and/or executive	 Governing bodies	 Commissioning and funding bodies
<p>Informed about opportunities to use their lived experience for change and contribute to systems, structures, policies, processes, practices, programs and services they interact with or are supported by.</p>	<p>Encouraged and supported to assist the person they support to use their lived experience for change and contribute to systems, structures, policies, processes, practices, programs and services?</p> <p>Informed about opportunities to use their lived experience for change.</p>	<p>Take up opportunities to use their own lived experience in leadership and governance structures.</p>	<p>Encourage and support people with lived experience expertise to use it in leadership and governance structures.</p>	<p>Ensure operational processes support people with lived experience expertise to be embedded in leadership and governance structures.</p>	<p>Oversee the development of strategic priorities that embed lived experience expertise in leadership and governance structures.</p>	<p>Establish and maintain contractual requirements for funding recipients to embed lived experience expertise in leadership and governance structures?</p> <p>Set targets for the ratio of frontline and leadership lived experience (peer) roles throughout tender processes for all types of work, not just service delivery.</p>



 Person	 Carers, family, kin and other supporters of choice	 Lived experience (peer) workforces	 Non-lived experience (peer) workforces	 Management and/or executive	 Governing bodies	 Commissioning and funding bodies
<p>Partnered with and encouraged to contribute to systems, structures, policies, processes, practices, programs and services that are delivered on or implemented by competent, high-quality, safe and supported workforces that value lived experience.</p>	<p>Partnered with and encouraged to contribute to systems, structures, policies, processes, practices, programs and services that are delivered on or implemented by competent, high-quality, safe and supported workforces that value lived experience.</p>	<p>Use their lived experience to deliver competent, high quality and safe systems, structures, policies, processes, practices, programs and services.</p> <p>Engage in professional learning that contributes to building capability and capacity.</p>	<p>Value the lived experience (peer) workforces and deliver competent, high quality and safe systems, structures, policies, processes, practices, programs and services that value lived experience.</p>	<p>Ensure operational processes support workforces to provide competent, high quality and safe systems, structures, policies, processes, practices, programs and services; including valuing and enabling the lived experience (peer) workforces to use their lived experience effectively.</p> <p>Appropriately fund lived experience (peer) workforces and ensure funding allocation is representative of need.</p>	<p>Oversee the development of strategic priorities that ensure workforces provide competent, high quality and safe systems, structures, policies, processes, practices, programs and services that value and embed lived experience.</p> <p>Invest in structures that embed the voice, influence and leadership of people with lived experience and build their capability to do so effectively.</p> <p>Set a narrative around the lived experience (peer) workforce to ensure it is strategically embedded in to systems, structures, policies, processes, practices, programs, services and operational models.</p>	<p>Establish and maintain contractual requirements for funding recipients to develop and implement governance processes that ensure workforces provide competent, high quality and safe systems, structures, policies, processes, practices, programs and services that value and embed lived experience.</p>

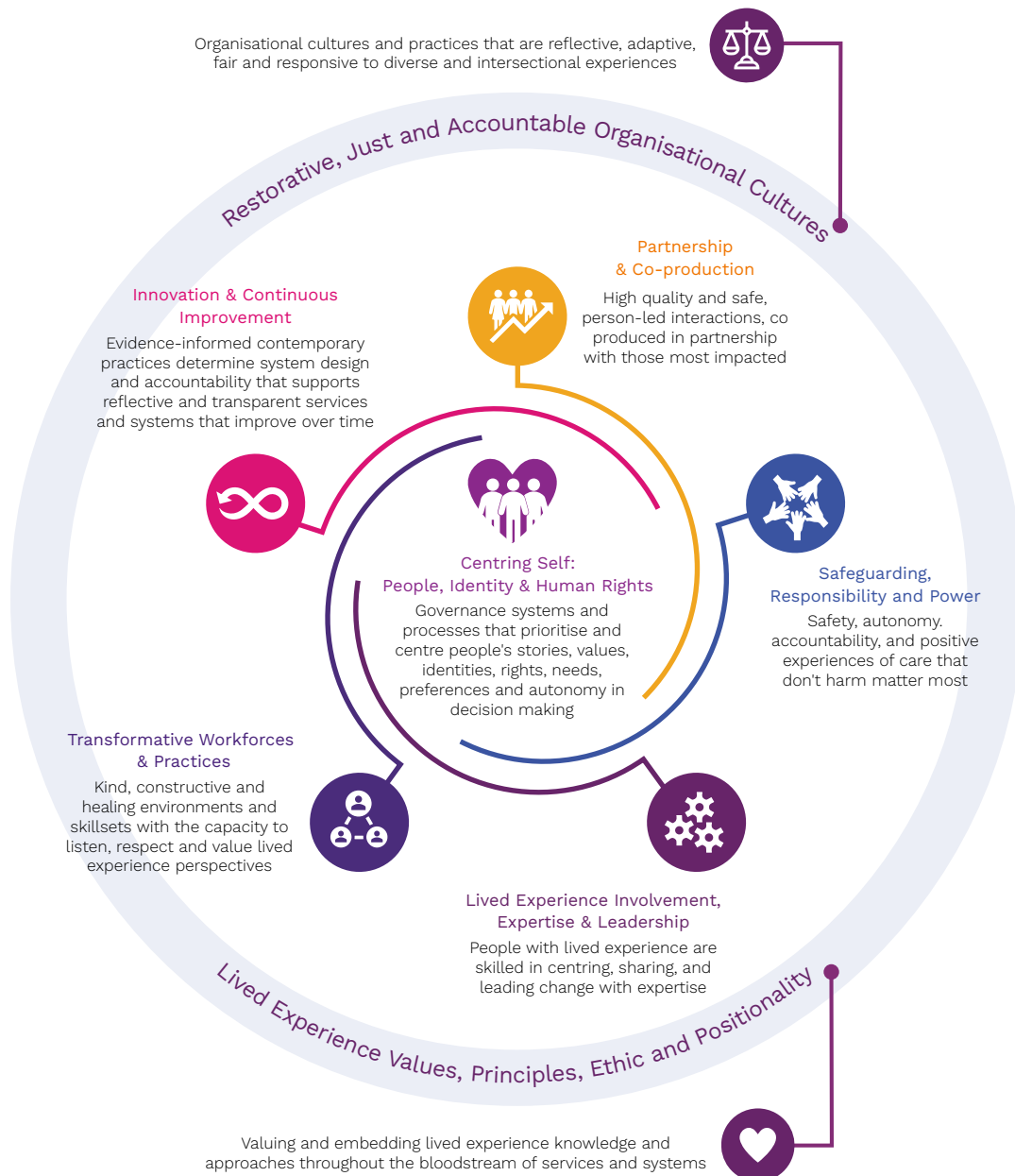


 Person	 Carers, family, kin and other supporters of choice	 Lived experience (peer) workforces	 Non-lived experience (peer) workforces	 Management and/or executive	 Governing bodies	 Commissioning and funding bodies
<p>Access opportunities to provide feedback on, improve and refine systems, structures, policies, processes, practices, programs and services.</p> <p>Access capacity-building opportunities to strengthen their contributions within involvement, partnership and leadership activities.</p>	<p>Access <u>and</u> support the person with lived experience to access, opportunities to provide feedback on, improve and refine systems, structures, policies, processes, practices, programs and services.</p>	<p>Use their lived experience to access opportunities to provide feedback on, improve and refine systems, structures, policies, processes, practices, programs and services.</p>	<p>Contribute to innovation and continuous improvement processes and support people with lived experience to access opportunities to provide feedback on, improve and refine systems, structures, policies, processes, practices, programs and services.</p>	<p>Ensure operational processes support people with lived experience to access opportunities to provide feedback on, improve and refine systems, structures, policies, processes, practices, programs and services.</p>	<p>Oversee the development of strategic priorities that support people with lived experience to access opportunities to provide feedback on, improve and refine systems, structures, policies, processes, practices, programs and services.</p>	<p>Establish and maintain contractual requirements for funding recipients to develop and implement governance processes that support people with lived experience to access opportunities to provide feedback on, improve and refine systems, structures, policies, processes, practices, programs and services.</p>

# What Success Looks Like

Lived experience governance intentionally embeds organisational cultures and systems that give primacy to centring or being led by lived experience perspectives, principles, and ways of working in the decision-making, oversight and evaluation of systems, structures, policies, processes, practices, programs and services.

The ways that organisations approach lived experience governance will be proportionate to the needs and size of the organisation, the complexity of the environments that they operate within, their aspired influence and the responsibility they take on to truly embed human rights and person-directed and -led approaches. The people that interact with or are supported by organisations are in the best position to judge success and the ways that is best measured. Below are indicators of success co-created throughout the development of the Framework.





## Enablers

This section considers the enablers needed to drive change within organisations and across systems to embed the Framework.

The key goal of the Framework is to build organisational cultures that centre the rights, needs, preferences, autonomy and decision-making power of people with lived experience and includes them in governance and decision-making processes. While this is an outcome, organisational culture change is also a key enabler of governance effectiveness and outcomes. Organisations with a strong lived experience culture are inclusive, adaptive, free from discrimination, accountable and justice oriented.

Culture change is often intangible and led by committed individuals, and will alone does not make it happen. The enablers listed below are interdependent and must be accompanied with a change in mindset for transformations to last.

Leaders and decision-makers at organisational and systems level are responsible for creating an authorising environment that enables a lived experience governance approach to embed and thrive. This requires addressing resourcing and business structures and supporting them to develop capability and partnerships. For these structural changes to have the greatest impact they must be accompanied with changed power dynamics and underpinned by a growth mindset that values and makes space for lived experience perspectives and practices.

## Accountability

To ensure the Framework is meaningful, avoids tokenistic lived experience governance and contributes to systems transformation, sector leaders and organisations must be accountable for implementing and embedding it.

Accountability means that people with lived experience, including lived experience leaders and people in designated lived experience (peer) roles, know what organisations are doing, know how they can be involved in decision-making and governance processes, and know that they have influence to change the systems, structures, policies, processes, practices, programs and services they interact with or are being supported by. The workforce sees that organisations value lived experience, that people are trusted and meaningfully supported to use their lived experience, and that lived experience expertise contributes to the organisation's purpose, strategy and governance. Program funders and commissioners, the service system and broader community value and benefit from the presence and wisdom of lived experience.

Accountability ties action to value, purpose and strategy. This means always acting ethically, and with responsibility to people with lived experience and the broader community. It provides the spaces and structures to non-judgementally check in, challenge and improve how things are done together.

The Framework offers a lens through which organisations can align their governance approaches with the rights, needs, preferences, autonomy and decision-making power embodied by the lived experience movement. The full potential of the ideas set out in the Framework will need concerted collective effort and advocacy at community, organisational, jurisdictional and federal level for this vision to be realised.



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*Accountability is when words and actions line up.*

ThinkTank  
Participant



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*What will be the outcome of the lived experience governance framework? What we are looking for, we are looking in terms of improving the wellbeing; improving capacity; or advancing in social justice; advancing participation in democracy.*

Interview  
Participant

Lived experience governance is an emergent space. Much of the work to embed and develop lived experience, and associated safety and quality measures, is happening at the same time.

When considering accountability for the implementation of the Framework, people responsible must very clearly acknowledge who is being heard from and who is not, ensuring that people and communities who experience more layers of marginalisation and systemic oppression will need to be invited in and included in ways that are deemed 'safe-enough' by them. Ultimately, accountability must be to people with lived experience and people who interact with or are supported by systems. Consider that the lived experience stakeholders to whom organisations owe accountability will have different expectations, and the way that organisations hold themselves to account will differ accordingly.

Organisational-level accountability means accountability to:

- People with lived experience who interact with or are supported by systems, structures, policies, processes, practices, programs and services.
- Workforces, particularly the lived experience (peer) workforces.
- The broader service system, including funders, commissioners and the lived experience community.

System-level accountability means accountability to:

- Program funders and commissioners.
- The service system, including partners and interfacing organisations.

Accountability at the system-level also includes people with lived experience being accountable to, and holding each other, to account.

# Enablers

## Resourcing

Budgets and timeframes support lived experience involvement and leadership.

People with lived experience are appropriately remunerated and provided with the resources and supports they need to participate.

## Business Processes

Business systems support the representation and leadership of people with lived experience.

Requirements for lived experience representation and leadership are built into contracts.

People with lived experience are involved in commissioning processes.

Priority is given to lived experience-led contractors and agencies.

## Capability Building

The organisation and non-lived experience workforce understand their readiness, willingness and capability for embedding lived experience.

The service has a clear purpose and rationale to underpin lived experience governance.

People with lived experience are supported to contribute to and lead governance approaches.

## Partnerships

The service develops reciprocal partnerships with lived experience communities.

Partnerships are resourced adequately.

# Accountability

## Organisational-level Accountability

Rights-based policies and procedures informed by people with lived experience, that are regularly reviewed and improved.

Regular, easy to understand communications.

It is easy to contact the right person within the service in a timely manner.

Organisations discuss their strengths and weaknesses openly and provide clear steps for involving people with lived experience in improving what they do.

Monitoring, evaluation and learning from a lived experience lens.

## System-level Accountability

Open and transparent communication about organisations' own accountability efforts, what they are doing and the opportunities for improvement.

Organisations build partnerships with the community and sector, based on mutual listening.

Key relationships with sector stakeholders are developed, collaboratively sharing what works, and pushing each other to improve.

Advocacy for lived experience leadership and involvement in system-level change.



# 6

# Attachments

Appendix One

Understanding Governance

Glossary of Acronyms and Language Used

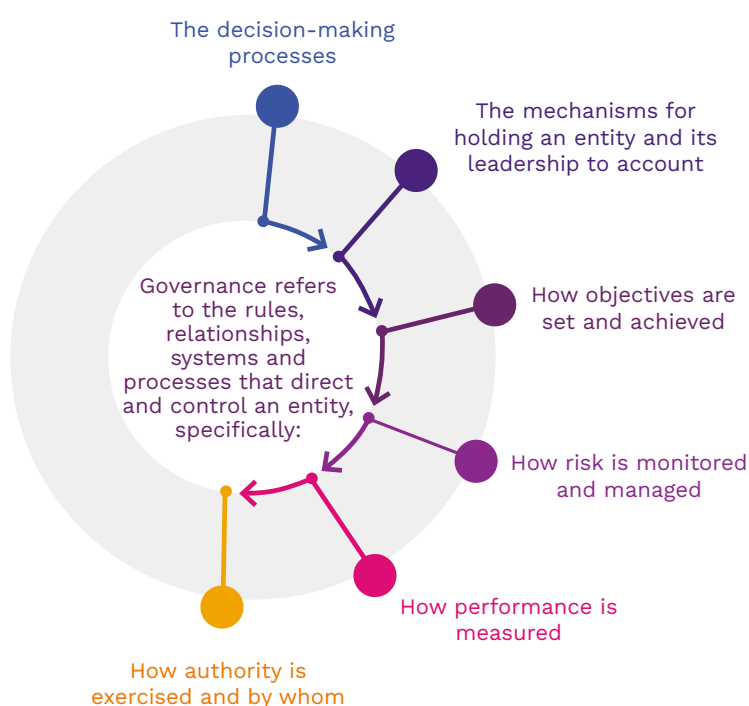
About LELAN



## Appendix One

# Understanding Governance

Governance has been described as *the operational and control mechanisms of a defined system that holds to account people and decisions made relating to ethics, risk, consent and administration that in turn define the overall governance system*<sup>54</sup>. It refers to rules, relationships, structures and processes that direct and control an organisation, specifically the governance and decision-making processes, accountability mechanisms, strategic direction and oversight, risk management and monitoring, performance measurement and delegation of authority.



Corporate governance<sup>55</sup> encompasses the establishment of systems and processes that shape, enable, and oversee management of an organisation. It is the activity, undertaken by governing bodies such as boards, of formulating strategy, setting policy, delegating responsibility, overseeing management, and ensuring that appropriate risk management and accountability arrangements are in place throughout the organisation.

The Australian Indigenous Governance Institute (AIGI)<sup>56</sup> clarifies that *Indigenous governance is not the same thing as organisational governance... What makes it Indigenous governance is the role that Aboriginal and Torres Strait Islander social and philosophical systems, cultural values,*

*traditions, rules and beliefs play in the governance of: processes—how things are done; structures—the ways people organise themselves and relate to each other; and institutions—the rules for how things should be done.*


Aboriginal and Torres Strait Islander governance<sup>57</sup> focuses on the importance of place, people, relationships and process for addressing power imbalances and achieving equitable outcomes and is predicated upon a distinct knowledge and value system that sits outside traditional notions of governance. Cultural

<sup>54</sup> Duke, D.L.M., Prictor, M., Ekinci, E., Hachem, M., Burchill, L.J. 2021 Culturally Adaptive Governance—Building a New Framework for Equity in Aboriginal and Torres Strait Islander Health Research: Theoretical Basis, Ethics, Attributes and Evaluation. *Int. J. Environ. Res. Public Health*, <https://doi.org/10.3390/ijerph18157943>

<sup>55</sup> Australian Commission on Safety and Quality in Health Care (ACSQHC), 2017, National Model Clinical Governance Framework, Sydney.

<sup>56</sup> Australian Indigenous Governance Institute (AIGI), 2023, Indigenous Governance Toolkit, 1.2 Indigenous governance section, accessed at <https://aigi.org.au/toolkit>

<sup>57</sup> Duke, D.L.M., Prictor, M., Ekinci, E., Hachem, M., Burchill, L.J. 2021 Culturally Adaptive Governance—Building a New Framework for Equity in Aboriginal and Torres Strait Islander Health Research: Theoretical Basis, Ethics, Attributes and Evaluation. *Int. J. Environ. Res. Public Health*, 18, 7943, <https://doi.org/10.3390/ijerph18157943>



Governance<sup>58</sup> ensures the *power and authority for Aboriginal people, their families and communities to guide and inform all health-related policies and practices across all business*. It explores the integration of governance alongside traditional ways of knowing and decision-making led by Aboriginal and Torres Strait Islander peoples and other culturally diverse communities.

Clinical governance<sup>59</sup> is a core component of corporate governance. It defines the relationships and responsibilities required to ensure good clinical outcomes ensuring that the community and health service organisations can be confident that structures are in place to deliver safe and high-quality health care, and continuously improve services.

Practice governance<sup>60</sup> is broader than clinical governance and has been defined as *the set of relationships and responsibilities established by a service provider between its management, workforce and stakeholders, including consumers*.

The role of a cultural governance framework is to ensure inclusion and alignment with cultural values and perspectives; the role of a clinical framework is to ensure the highest quality of clinical outcomes; and the role of a corporate governance framework is to ensure corporate cohesion, profit and accountability. The role then, of a lived experience governance framework, is to embed lived experience in governance for the purpose of centring and enhancing the rights, experiences, autonomy and decision-making power of people with lived experience.



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*Lived experience governance puts human rights, first and foremost. It values lived experience and doesn't see our experience as less than, let alone broken. I think it recognises that our vulnerability when used in the service of others, is a strength. It's not a weakness. It's a real, it's an amazing strength. It is the bridge, lived experience governance is the bridge, between services that have been actually delivering trauma rather than healing, and services that are human rights focused healing and loving. And based on relationship, rather than based on clinical outputs.*

Interview  
Participant

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<sup>58</sup> WA Country Health Service Cultural Governance Framework, 2021, accessed at <https://www.wacountry.health.wa.gov.au/-/media/WACHS/Documents/About-us/Publications/WACHS-Cultural-Governance-Framework-2021.pdf>

<sup>59</sup> Australian Commission on Safety and Quality in Health Care (ACSQHC), 2017, National Model Clinical Governance Framework, Sydney.

<sup>60</sup> Australian Commission on Safety and Quality in Health Care (ACSQHC), 2022, National Safety and Quality Mental Health Standards for Community Managed Organisations, Sydney.



# Glossary of Acronyms and Language Used

The Framework was written on the lands of the Kurna and Ngadjuri people. Within this document we use Aboriginal and Torres Strait Islander people to refer to First Nations peoples of Australia. While there is limited opportunity to do so within the Framework, where possible we have referred to Aboriginal and Torres Strait Islander peoples by their specific nation or language group.

**Aboriginal and Torres Strait Islander governance<sup>61</sup>** • Alongside cultural governance<sup>62</sup>, it recognises and incorporates the integration of governance alongside traditional ways of knowing and decision-making led by Aboriginal and Torres Strait Islander peoples and other culturally diverse communities. Community and health service organisations act to ensure the power and authority of and for Aboriginal people, their families and communities, guides and informs all health-related policies and practices. It is predicated upon a distinct knowledge and value system that sits outside traditional notions of governance and recognises the importance of people, place, relationships and process for addressing power imbalances and achieving equitable outcomes.

**Aboriginal and Torres Strait Islander lived experience<sup>63</sup>** • Recognises the effects of ongoing negative historical impacts and or specific events on the social and emotional experiences and wellbeing of Aboriginal and Torres Strait Islander peoples. The lived experience of Aboriginal and Torres Strait Islander peoples exists and cannot be separated from their cultural, spiritual, physical, emotional and mental wellbeing of the individual, family or community. This lived experience is also cumulative and intergenerational and takes into consideration Aboriginal and Torres Strait Islander people's ways of understanding social and emotional wellbeing.

**Accountable<sup>64</sup>** • The obligation to accept responsibility for one's actions. Individuals are accountable for their own actions and obliged to explain and provide evidence of their choices and decision-making. The accountability of community and health service organisations is to implement, monitor and evaluate systems that ensure the delivery of safe quality care, maintain and comply with legislated obligations, and met standards and codes of conduct and practice that ensure consumers are better positioned to have their rights, choices and decisions are respected and met to best reach their health and care goals.


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<sup>61</sup> Duke, D.L.M., Prictor, M., Ekinci, E., Hachem, M., Burchill, L.J. Culturally Adaptive Governance—Building a New Framework for Equity in Aboriginal and Torres Strait Islander Health Research: Theoretical Basis, Ethics, Attributes and Evaluation. *Int. J. Environ. Res. Public Health* 2021, 18, 7943. <https://doi.org/10.3390/ijerph18157943>

<sup>62</sup> WA Country Health Service Cultural Governance Framework accessed at <https://www.wacountry.health.wa.gov.au/~/-/media/WACHS/Documents/About-us/Publications/WACHS-Cultural-Governance-Framework-2021.pdf>

<sup>63</sup> Aboriginal and Torres Strait Islander Lived Experience Centre 2020 Black Dog Institute accessed at <https://www.blackdoginstitute.org.au/education-services/aboriginal-and-torres-strait-islander-network/>

<sup>64</sup> Community Services Quality Governance Framework, State of Victoria, Department of Health and Human Services 2018 [https://www.dhhs.vic.gov.au/sites/default/files/documents/201810/Community%20services%20quality%20governance%20framework\\_0.pdf](https://www.dhhs.vic.gov.au/sites/default/files/documents/201810/Community%20services%20quality%20governance%20framework_0.pdf)



**Adaptive culture** • The ability of an organisation to adapt quickly and effectively to internal and external pressures and indicators for change<sup>65</sup> and to identify and respond to potential and actual challenges to find the best outcome/s. Adaptive organisational cultures promote better participation and engagement through transparent communication, equal responsibility and developing capacity for shared learning and integrated and effective decision-making .

**Allyship** • An ongoing process where other individuals and groups, actively support or advocate for the interests and rights of a marginalised or underrepresented group to which they do not personally identify or are not a member of, to promote and aspire to advance an organisational culture of inclusion through intentional, positive and conscious efforts.

**Culturally and Linguistically Diverse (CALD)<sup>66</sup>** • Refers to the many and diverse Australian communities that originally came from other countries and ancestries and are different from those Australians born here generation and generation. CALD Communities identify as their country, nationality or ancestry of origin.

**Carer** • Someone who has experience of supporting and providing assistance to another person which may be a family member, friend or neighbour, or as part of a kinship relationship through mental health challenges, or other health and life support needs, use of community and health service, periods of healing and/or personal recovery.

**Capability<sup>67</sup>** • The power or extent to which someone or something (e.g. an organisation or system) is able to do something.

**Capacity** • The maximum amount someone or something can produce, contain or achieve. In health and social services this may be dependent on physical, financial and/or human resources and influenced by capability to achieve it.

**Clinical governance<sup>68</sup>** • A core component of corporate governance. It defines the relationships and responsibilities required to ensure good clinical outcomes ensuring that the community and health service organisations have the evidence and can be confident that structures and systems are in place to deliver safe and high-quality health care, and continuously improve services.

**Community<sup>69</sup>** • Individuals may, at any time, act as a collective of individuals, populations, networks or organisations, who represent or bring a collective voice of the interests of health consumers and of specific affected communities. While some communities may connect through a local, regional or group interest, others may share a cultural background. Some communities may be geographically dispersed but linked through an interest in, or experience.

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<sup>65</sup> Management Advisory Service. n.d. Adaptive Corporate Culture. [http://www.mas.org.uk/wellbeing-performance/adaptive\\_corporate\\_culture.html#:~:text=Introduction,be%20more%20resilient%20against%20stress](http://www.mas.org.uk/wellbeing-performance/adaptive_corporate_culture.html#:~:text=Introduction,be%20more%20resilient%20against%20stress)

<sup>66</sup> Pham, T.T.L., Berecki-Gisof, J., Clapperton, A., O'Brien, K.S., Liu, S., Gibson, K. Definitions of Culturally and Linguistically Diverse (CALD): A Literature Review of Epidemiological Research in Australia Int J Environ Res Public Health 2021 doi <https://doi.org/10.3390%2Fijerph18020737>

<sup>67</sup> Oxford English Dictionary <https://www.oed.com/>

<sup>68</sup> Australian Commission on Safety and Quality in Health Care. National Model Clinical Governance Framework. Sydney: ACSQHC; 2017.

<sup>69</sup> Canadian Institute of Health Research Ottawa 2014



**Consumer** • Someone who has personal experience of mental health challenges, service use, periods of healing/personal recovery.

Note: Lived experience is frequently used as an umbrella term that conflates the experiences of consumers with the experiences of carers, family, kin and other supporters of choice. While some people who have personal lived experience are also carers, and there are some issues where consumer and carer perspectives align, in some cases the interests of consumers are in clear opposition to those of carers. It is not possible for one person to authentically represent both positions at the same time with integrity. To avoid tokenism, both experiences must be recognised as independent and separate of each other and both be given opportunities for involvement and representation matched to the context and issue being explored<sup>70</sup>.

**Consumer or Person directed care** • Builds on person-centred care and strengthens consumer choice and self-determination, where decisions about what services are required and desired are made by the consumer. It also emphasises the need for flexible and accessible services, with a focus on seeking supports to meet a wide variety of recovery interests. It promotes a dignity of risk or risk tolerant approach and reflects a disability rights approach, not based on ‘practitioner privilege capability’ rather than assessing the person’s capacity. CDC acknowledges that a range of different services and practitioners are often chosen by consumers<sup>71</sup>.

**Continuous improvement** • A progressive and incremental improvement of processes, systems, safety and quality of care. It is responsive to consumer and community needs and improving consumer and community experience and health outcomes.. It is a continuous and ongoing effort to achieve measurable improvements in the efficiency, effectiveness, performance, accountability, outcomes, regulatory compliance and other indicators of quality and safety.<sup>72</sup>

**Co-production** • A comprehensive approach to making collaborative change that prioritises power sharing, inclusiveness and openness<sup>73</sup>. A co-production approach is a way of working equalised power imbalances and that positions consumers to participate in, or leading to help define the problem, design and deliver the solution, and evaluate the outcome<sup>74</sup>. It requires the inclusion of lived experience expertise from earliest outset. The approach is value-driven and built on the principle that those who use a service are best placed and have the right to help design it<sup>75</sup>.

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<sup>70</sup> Hodges, E. and Reid, A. 2021, A guide for enabling lived experience involvement and leadership to thrive and have impact in your organisation. SA Lived Experience Leadership & Advocacy Network (LELAN), Adelaide. [https://www.lelan.org.au/wp-content/uploads/2021/08/Guide\\_Enabling-LEx-to-Thrive-in-Your-Organisation.pdf](https://www.lelan.org.au/wp-content/uploads/2021/08/Guide_Enabling-LEx-to-Thrive-in-Your-Organisation.pdf)


<sup>71</sup> Loughhead, M., McDonough, J., Baker, K., Rhodes, K., Macedo, D., Ferguson, M., McKellar, L. and Procter, N. Person-centred and Consumer Directed Mental Health Care: Transforming Care Experiences, prepared for the National Mental Health Commission, University of South Australia; 2023. <https://doi.org/10.25954/jkqx-ay14>

<sup>72</sup> Minnesota Department of Health. 2022. Continuous Quality Improvement. <https://www.health.state.mn.us/communities/fhv/cqi.html>

<sup>73</sup> Co-Create. N.D. What is Co-Production? <https://www.wearecocrete.com/what-we-do/what-is-co-production/>

<sup>74</sup> Roper, C., Grey, F. & Cadogan, E. Co-production 2018. Putting principles into practice in mental health contexts. [https://health-sciences.unimelb.edu.au/\\_\\_data/assets/pdf\\_file/0007/3392215/Coproduction\\_putting-principles-into-practice.pdf](https://health-sciences.unimelb.edu.au/__data/assets/pdf_file/0007/3392215/Coproduction_putting-principles-into-practice.pdf)

<sup>75</sup> Social care institute for excellence Co-production UK 2022 <https://www.scie.org.uk/co-production/what-how>



**Corporate governance**<sup>76</sup> • Encompasses the establishment of systems and processes that shape, enable, and oversee management of an organisation. It is the activity, undertaken by governing bodies such as boards, of formulating strategy, setting policy, delegating responsibility, overseeing management, and ensuring that appropriate risk management and accountability arrangements are in place throughout the organisation.

**Cultural Responsiveness**<sup>77</sup> • In Australia, cultural responsiveness has been shaped as strengths-based, action-orientated approaches that enable Aboriginal and Torres Strait Islander people to experience cultural safety. It is a negotiated process of what constitutes culturally safe health care as decided by the recipient of that care. It is about the centrality of culture and how that shapes each individual, their worldviews, values, beliefs, attitudes, and interactions with others. It requires strengths-based approaches and recognises that if culture is not factored into health care and treatment, the quality and probable impact of that care and treatment is likely to be diminished.

**Cultural Safety**<sup>78 79</sup> • Aboriginal and Torres Strait Islander peoples experience cultural safety when their cultural strengths, preferences and ways of being are visible and embedded in planning, implementation, evaluation, processes and policies. It is about creating an environment that is safe for Aboriginal and Torres Strait Islander peoples through shared respect, shared meaning and shared knowledge, ensuring there is no assault, challenge or denial of their identity and experiences. It requires:

- knowledge and respect for self: awareness of how one's own cultural values, knowledge, skills and attitudes are formed and affect others, including a responsibility to address their unconscious bias, racism and discrimination; and
- knowledge and respect for Aboriginal and Torres Strait Islander people: knowledge of the diversity of Aboriginal and Torres Strait Islander peoples, communities and cultures, and the skills and attitudes to work effectively with them.

**Culture** • May have different meanings depending on context. When referring to cultural groups such as Aboriginal and Torres Strait Islander peoples and their connection to culture, it can be defined as a body of collectively shared values, principals, practices and customs and traditions<sup>80</sup> and includes systems of knowledge, law and practices that comprise their heritage. When referring to an organisational culture, it refers to the shared values, beliefs, norms, practices, and behaviours that characterise an organisation and shape its collective identity, values, and way of functioning. It influences how people interact with one another, how decisions are made, and how work is conducted within the organisation.

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<sup>76</sup> Australian Commission on Safety and Quality in Health Care. National Model Clinical Governance Framework. Sydney: ACSQHC; 2017.

<sup>77</sup> Indigenous Allied Health Australia (2019) Cultural Responsiveness in Action: An IAHA Framework [https://iaha.com.au/wp-content/uploads/2020/08/IAHA\\_Cultural-Responsiveness\\_2019\\_FINAL\\_V5.pdf](https://iaha.com.au/wp-content/uploads/2020/08/IAHA_Cultural-Responsiveness_2019_FINAL_V5.pdf)

<sup>78</sup> *ibid.*

<sup>79</sup> Aboriginal and Torres Strait Islander cultural safety Department of Health Victoria <https://www.health.vic.gov.au/health-strategies/aboriginal-and-torres-strait-islander-cultural-safety>

<sup>80</sup> Gee, G., Dudgeon, P., Schultz, C., Hart, A., & Kelly, K. (2014). Social and Emotional Wellbeing and Mental Health: An Aboriginal Perspective. In P. Dudgeon, M. Milroy, & R. Walker. (Eds.), Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice – Revised Edition (p.55–68). Canberra: Commonwealth of Australia. <https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/working-together-second-edition/wt-part-1-chapt-4-final.pdf>



**Dignity of Risk**<sup>81</sup> • A way of saying a person has the right to live the life they choose, even if their choices involve some risk. If something a person wants to do involves some risk to them, service providers should support them and their representative to understand the risks and manage them as part of ensuring the person's rights to choice and control and using a strengths based approach. Duty of care is often used by service providers to 'veto/override' a person's dignity of risk. This is a misrepresentation of duty of care which is the legal responsibility set up to ensure people are not harmed by the service, the organisation and its staff provides and does not mean protecting the person from themselves and their own choices<sup>82</sup>.

**Diversity**<sup>83</sup> • The demographic mix of a specific collection of people, taking into account elements of human difference. It is these differences that makes each person unique and includes but is not limited to their; backgrounds, personality, intersex status, religious beliefs, educational level, professional skills, work experience, socio-economic background, career obligations, geographic location and/or many other factors relevant to the individual, life experiences and beliefs, all of the things that make them who they are. It is a combination of their differences that shape their view of the world, their perspective and their approach<sup>84</sup>.

**Governance** • The operational and control mechanisms of a defined system that holds to account people and decisions made relating to ethics, risk, consent and administration that in turn define the overall governance system<sup>85</sup>. It refers to rules, relationships, structures and processes that direct and control an organisation, specifically the governance and decision-making processes, accountability mechanisms, strategic direction and oversight, risk management and monitoring, performance measurement and delegation of authority.

**Epistemic Justice** • The idea that we can be unfairly discriminated against in our capacity as a knower based on prejudices about the speaker, such as gender, social background, ethnicity, race, sexuality, tone of voice, accent, and so on<sup>86</sup>.

**Equality**<sup>87</sup> • Means all people are treated equally. An equality strategy seeks to improve access to, or quality of, systems or services for all individuals and populations. This approach is based on the expectation that improved systems or services for everyone will improve outcomes for those experiencing inequities. It may not, however, make up for the systemic deficits in resources and opportunities experienced by historically oppressed populations.

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<sup>81</sup> Aged Care Quality and Safety Commission 2018, Guidance and Resources for Providers to Support the Aged Care Quality Standards. <https://www.agedcarequality.gov.au/resources/guidance-and-resources-providers-support-aged-care-quality-standards>

<sup>82</sup> Dignity of risk vs negligence – What is an aged care provider's duty of care? (2019) Kott Gunning Lawyers <https://www.kottgunn.com.au/updates/business-commercial/dignity-risk-vs-negligence-aged-care-providers-duty-care/>


<sup>83</sup> Power Moves Assessment Guide for Equity and Justice 2019 <https://www.ncfp.org/wp-content/uploads/2020/04/Power-Moves-Assessment-Guide-for-Equity-and-Justice-NCRP-2019.pdf>

<sup>84</sup> Only skin Deep? Re-examining the business case for diversity. Deloitte 2011

<sup>85</sup> Duke, D.L.M., Pricor, M., Ekinci, E., Hachem, M., Burchill, L.J. Culturally Adaptive Governance—Building a New Framework for Equity in Aboriginal and Torres Strait Islander Health Research: Theoretical Basis, Ethics, Attributes and Evaluation. *Int. J. Environ. Res. Public Health* 2021, 18, 7943. <https://doi.org/10.3390/ijerph18157943>

<sup>86</sup> Byskov, M.F. (2021), What Makes Epistemic Injustice an "Injustice"? *J Soc Philos*, 52: 114-131. <https://doi.org/10.1111/josp.12348>

<sup>87</sup> Power Moves Your essential philanthropy assessment for equity and justice <https://www.ncfp.org/wp-content/uploads/2020/04/Power-Moves-Assessment-Guide-for-Equity-and-Justice-NCRP-2019.pdf>



**Equity<sup>88</sup>** • Is only achieved when an advantage or disadvantage based on but not limited to any and all aspects of diversity that can no longer be predicted. An equity framework is a proactive, strategic approach to improving outcomes that accounts for structural differences in opportunities, burdens and needs in order to advance targeted solutions that fulfill the promise of true equality for all.

**Human Rights<sup>89</sup>** • Rights inherent to all human beings, regardless of race, sex, nationality, ethnicity, language, religion, or any other status. Human rights include the right to life and liberty, freedom from slavery and torture, freedom of opinion and expression, the right to work and education, and many more.

**Indigenous Governance<sup>90</sup>** • Indigenous governance is not the same thing as organisational governance. What makes it Indigenous governance is the role that Aboriginal and Torres Strait Islander social and philosophical systems, cultural values, traditions, rules and beliefs play in the governance of: processes—how things are done; structures—the ways people organise themselves and relate to each other; and institutions—the rules for how things should be done.

**Innovation** • A multi-stage process whereby organisations transform ideas into new or improved processes, products or services to differentiate, compete or advance<sup>91</sup>. ‘Health innovation’ improves the efficiency, effectiveness, quality, sustainability, safety, and/or affordability of healthcare. This definition includes ‘new or improved’ health policies, practices, systems, products and technologies, services, and delivery methods that result in improved healthcare - World Health Organization<sup>92</sup>.

**Inclusion<sup>93</sup>** • The degree to which diverse individuals and groups are able to participate fully in the governance and decision-making processes about themselves, their own situation and about things than may impact them. The practice or policy of inclusion refers to providing equal access to opportunities and resources for people who might otherwise be excluded or marginalised to be included and participate in decision-making.

**Intersectionality** • A concept that describes the interconnected nature of social categories such as (but not limited to) race, gender, sexuality, class, and ability, and how they interact to shape individual experiences and social inequalities. Marginalised individuals often face multiple forms of oppression simultaneously, and their experiences cannot be fully understood by looking at just one axis of oppression<sup>94</sup>. Intersectionality recognises that the intersections of various social categories create unique experiences of discrimination and privilege. The point of understanding intersectionality is to also understand that different forms of oppression and privilege are not experienced independently but are intertwined and must be considered together to understand the complexities of social inequality.

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<sup>88</sup> Power Moves Your essential philanthropy assessment for equity and justice <https://www.ncfp.org/wp-content/uploads/2020/04/Power-Moves-Assessment-Guide-for-Equity-and-Justice-NCRP-2019.pdf>

<sup>89</sup> United Nations <https://www.un.org/en/global-issues/human-rights>

<sup>90</sup> Australian Indigenous Governance Institute (AIGI) Indigenous Governance Toolkit, 1.2 Indigenous governance section, AIGI website, 2023. <https://aigi.org.au/toolkit>


<sup>91</sup> Baregheh, A., Rowley, J., Sambrook, S. 2009. "Towards a multidisciplinary definition of innovation". *Management Decision*. 47 (8): 1323–1339. doi:10.1108/00251740910984578. ISSN 0025-1747

<sup>92</sup> Kimble, L., & Massoud, R.M. 2016. What do we mean by Innovation in Healthcare? *EMJ*. <https://www.emjreviews.com/innovations/article/what-do-we-mean-by-innovation-in-healthcare/>

<sup>93</sup> Power Moves Assessment Guide for Equity and Justice 2019 <https://www.ncfp.org/wp-content/uploads/2020/04/Power-Moves-Assessment-Guide-for-Equity-and-Justice-NCRP-2019.pdf>

<sup>94</sup> Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. *University of Chicago Legal Forum*, 139-167





**Lived Experience** • Personal experience(s) of a particular issue, such as mental health challenges or alcohol and other drug use, and the living despite, that have caused life as we knew it to change so significantly we have to reimagine and redefine ourselves, our place in the world and our future plans. It is informed by the expertise, the collective knowledge of the lived experience movement and, importantly, it's about learning how to use those experiences in a way that's useful to other people<sup>95</sup> In its broadest context, it is a person's direct and personal experiences and choices, positive and negative, the knowledge they have gained and the impact to them of these experiences and choices. This direct lived experience affords the person an authentic voice through their unique insight that can challenge assumptions, motivate organisations to do things differently and pinpoint areas for change<sup>96</sup>.

**Lived experience expertise** • The process of applying what has been learned through a person's lived experience to inform and transform systems, services and individual outcomes for those impacted by mental distress, social issues or injustice for the benefit of others.<sup>97</sup>

**Lived experience governance** • Lived experience governance intentionally embeds organisational cultures and systems that give primacy to centring or being led by lived experience perspectives, principles, and ways of working in the decision-making, oversight and evaluation of systems, structures, policies, processes, practices, programs and services.

**Lived experience leaders** • People who connect their personal, professional and socio-political worlds in unique ways to lead change, linking local experience with organisational and systems change endeavours. They operate within and outside of roles, organisations and settings<sup>98</sup>.

**Lived experience leadership**<sup>99</sup> • Includes informal and formal activity which promote the values and goals of lived experience as relating to empowerment, peer services, social justice and citizenship. Leaders speak up to influence community awareness, organisational culture, policy and politics; leaders create space, pathways and inclusion with others; leaders prompt and support change.

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<sup>95</sup> Byrne, L., & Wykes, T., 2020, A role for lived experience mental health leadership in the age of Covid-19, *Journal of Mental Health*, 29:3, 243-246, DOI: 10.1080/09638237.2020.1766002

<sup>96</sup> The role of lived experience in creating systems change Evaluation of fulfilling lives: Supporting people with multiple needs Report 2022 <https://www.bht.org.uk/wp-content/uploads/2021/03/The-role-of-lived-experience-in-creating-systems-change-2020-1.pdf>

<sup>97</sup> Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., Darwin, L., Castles, C., Craze, L., Saunders, M. National Lived Experience Workforce Guidelines. 2021, National Mental Health Commission

<sup>98</sup> Hodges, E., Loughhead, M., McIntyre, H. & Procter, N.G. 2021. The Model of Lived Experience Leadership. LELAN and UniSA, Adelaide

<sup>99</sup> Loughhead, M., Hodges, E., McIntyre, H., and Procter, N.G. 2021, A Roadmap for strengthening lived experience leadership for transformative systems change in South Australia, SA Lived Experience Leadership and Advocacy Network and University of South Australia



**Lived experience (peer) worker** • Anyone who works in a designated role who utilises their lived experience and lived experience values to benefit others with lived experience at either individual, operational or systemic levels to influence and drive change<sup>100</sup>. Lived experience workers roles can be direct (e.g. peer support roles) or indirect (e.g. lived experience academic, lived experience leader etc).

Lived experience workers draw on their life-changing experiences of mental or emotional distress, service use, and recovery/healing, and their experiences, or the impact of walking beside and supporting someone through these experiences, to build relationships based on collective understanding of shared experiences, self-determination, empowerment, and hope<sup>101</sup>.

**Lived experience (peer) workforces** • Workforces which are made up of people who are employed in paid positions that require lived experience as an essential employment criterion, regardless of position type or setting. This is a professional approach in which diverse personal experience-based knowledge is applied within a consistent framework of values and principles<sup>102</sup>.

Note: The pluralisation of lived experience (peer) workforces acknowledges the dynamic and differentiated experiences of those who are working from carer or consumer perspectives, alongside acknowledging the different fields, communities and settings which lived experience can be utilised in, including mental health, AOD, LGBTQIA+, CALD, Aboriginal and Torres Strait Islander, NDIS, Acute, etc.

**LGBTQIA+** • A diverse community including people who are lesbian, gay, bisexual, trans, queer, intersex, asexual and others who don't align or identify with being cisgender and heterosexual.

**Peer work/Peer support** • Sometimes considered a subset of the wider lived experience (peer) workforces, although language differences exist across jurisdictions. It predominantly refers to supporting others through recovery. Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria but rather understanding another's situation empathically through the shared experience of emotional and psychological pain. When people find affiliation with others they feel are 'like' them, they feel a connection. This connection, or affiliation, is a deep, holistic understanding based on mutual experience where people are able to 'be' with each other without the constraints of traditional (expert/patient) relationships<sup>103</sup>.

**Personhood**<sup>104</sup> • An essential characteristic of the human species - the quality or sense, of being an individual person who has self-agency. This self-agency includes conditions of rationality, consciousness of thought, the capacity for reciprocity and communication and the capacity to make decision and choices both right and wrong. Personhood is a relational (both personal and interpersonal) construct that personhood is a conditional state of value defined by society.<sup>105</sup>

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<sup>100</sup> Hodges, E., and Reid, A., 2021, A guide for enabling lived experience involvement and leadership to thrive and have impact in your organisation. SA Lived Experience Leadership & Advocacy Network (LELAN)


<sup>101</sup> Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., Darwin, L., Castles, C., Craze, L., Saunders, M. National Lived Experience Workforce Guidelines. 2021, National Mental Health Commission

<sup>102</sup> *ibid.*

<sup>103</sup> Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal*, 25(2), 134–141. <https://doi.org/10.1037/h0095032>

<sup>104</sup> Concept of Personhood. Centre for Health Ethics School of Medicines, University of Missouri <https://medicine.missouri.edu/centers-institutes-labs/health-ethics/faq/personhood>

<sup>105</sup> White F.J. Personhood: an Essential Characteristic of the Human Species 2013 Feb 1. doi: 10.1179/0024363912Z.00000000010



**Partnership** • A bringing together individuals and groups focussed on improving the health experience and health outcomes. Partners may be individuals and or groups, community organisations, sectors, governmental or non-governmental agencies, who work together for a common goal, based on mutually agreed roles and principles<sup>106</sup>. Partnering with a person/consumer in their own care is an essential component of person-centred care.

**Practice governance** • The set of relationships and responsibilities established by a service provider between its management, workforce and stakeholders, including consumers <sup>107</sup>

**Power** • The advantage held by those at the top of hierarchies based on race, class, gender, sexual orientation, religion, ability, geography, and other characteristics<sup>108</sup>. Power in policy processes as it relates to health equity involves multiple factors, including government, industry and public interest organisations and civil society, and that these actors hold and exert different types of power, and use them in different forms and spaces<sup>109</sup>.

**Power imbalance**<sup>110</sup> • Exists when one, or a group of members of the partnership, is able to dominate decision- making or otherwise asserts power in ways that disadvantages other partners and is not in the best interest towards achieving the partnership objectives. It must be acknowledged that a power imbalance exists between the consumer and health practitioner and can be mitigated by a person-centred care approach.

**Positionality** • How differences in social position and power shape identities and access in society<sup>111</sup>.

**Principles** • A set of propositions that serves as the foundation of fundamental truth. In relation to lived experience these principles flow from values, and shape how lived experience work is practiced and embody the character and philosophy of Lived Experience workforce. These principles are written from the perspective of the Lived Experience workforce. However, principles inform practice and are also intended to guide and inform commissioning and funding bodies, policy makers and organisations<sup>112</sup>.

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<sup>106</sup> Abeykoon P. Partnerships in Health Development. *Journal of Health Management*. 2021;23(1):143-154. doi:10.1177/0972063421995007

<sup>107</sup> Australian Commission on Safety and Quality in Health Care. National Safety and Quality Mental Health Standards for Community Managed Organisations. Sydney: ACSQHC; 2022

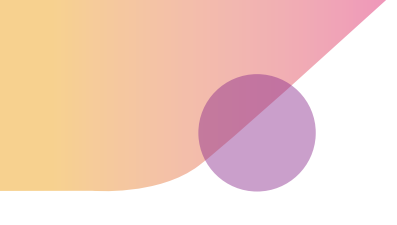
<sup>108</sup> Heller, J.C. PhD., Little, O.M. PhD., Faust, V. MPA., Tran, P. MPHv., Givens, M.L. PhD., Ayers, J. MPH, RN., Farhang, L. MPH. Theory in Action: Public Health and Community Power Building for Health Equity. *Journal of Public Health Management and Practice* 29(1):p 33-38, January/February 2023. | DOI: 10.1097/PHH.0000000000001681

<sup>109</sup> Friel, S., Townsend, B., Fisher, M., Harris, P., Freeman, T., & Baum, F. (2021). Power and the people's health. *Social science & medicine*, 282, 114173.

<sup>110</sup> Anticipating, managing and mitigating power imbalances, The Partnering Initiative <https://www.thepartneringinitiative.org/wp-content/uploads/2018/12/Managing-power-imbbalances.pdf>

<sup>111</sup> The University of British Columbia. n.d. Positionality & Intersectionality. <https://indigenousinitiatives.ctlt.ubc.ca/classroom-climate/positionality-and-intersectionality/#:~:text=Positionality%20refers%20to%20the%20how,identities%20and%20access%20in%20society>

<sup>112</sup> Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., Darwin, L., Castles, C., Craze, L., Saunders, M. National Lived experience Workforce Guidelines. 2021, National Mental Health Commission



**Responsibility** • Being responsible, accountable, or answerable for something that is within one's control, management or power<sup>113</sup>. In the context of care, is a commitment to the prevention and management of care concerns through systematic approaches in service culture, training, reporting, and review processes<sup>114</sup>.

**Restorative Just Culture**<sup>115</sup> • Aims to repair trust and relationships damaged after an incident. It allows parties to discuss how they have been affected, and collaboratively decide what should be done to repair the harm. The goals of restorative just culture is to accept appropriate responsibility for what has happened, recognise the seriousness of harms caused, humanise the people involved, allow for emotional healing and address the causes of harm.

**Risk** • Is the likelihood that an event will occur that will cause some type of undesirable effect. Risk events can occur anywhere, anytime. They may be predictable or not, controllable or not, and caused by internal or external variables. Risk exists along a spectrum, and identical events may be deemed more or less “risky” by different parties depending on their perspectives<sup>116</sup>.

This cannot be seen in isolation of dignity or risk where people with lived experience having the right for choice and control and dignity of risk, but health providers breach this right when assessing risk against duty of care and determining a person's of capacity using a reductive rather than strengths-based approach.

**Safe-enough** • Provides visibility and acceptance of the reality that some people, due to past experiences of harm, discrimination or coercion and restraint do not feel safe regardless of what setting they're in. As the individual cannot feel wholly safe, creating an environment in which the individual feels safe-enough becomes the aim of those trying to create positive, meaningful environments that allow for vulnerability and authenticity.

**Safeguarding**<sup>117</sup> • To assess the risk of, and take action to promote, protect and prevent harm to the health, wellbeing and human rights of a person to live free from abuse, neglect, mistreatment or exploitation.

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<sup>113</sup> <https://www.dictionary.com/browse/responsibility>

<sup>114</sup> Department for Child Protection. 2021. Service provider responsibilities in the management of care concerns. <https://www.childprotection.sa.gov.au/documents/service-providers/proposed-service-provider-responsibilities-management-care-concerns.pdf>

<sup>115</sup> Dekker, S. 2018. Restorative Just Culture Checklist. <https://www.safetydifferently.com/wp-content/uploads/2018/12/RestorativeJustCultureChecklist-1.pdf>

<sup>116</sup> Power Moves Your essential philanthropy assessment for equity and justice <https://www.ncfp.org/wp-content/uploads/2020/04/Power-Moves-Assessment-Guide-for-Equity-and-Justice-NCRP-2019.pdf>

<sup>117</sup> SA Health. 2023. Adult Safeguarding Unit. <https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/departement+for+health+and+wellbeing/office+for+ageing+well/adult+safeguarding+unit/adult+safeguarding+unit>



**Self** • An individual as the object of that individual's own reflective consciousness. One's self is one's sense of who they are, deep down one's identity. It is the totality of the individual, consisting of all characteristic attributes, lived experience, conscious and unconscious, mental and physical<sup>118</sup>. From an Aboriginal and Torres Strait Islander collectivist perspective, self is also viewed as inseparable from, and embedded within, family and community<sup>119</sup>.

**Self-determination**<sup>120</sup> • Each individual has choice in determining how their lives are governed and their development paths. They participate in decisions that affect their lives. This includes a right to formal recognition of their group identities and have control over their lives and future including their economic, social and cultural development.

**Values** • The things that are important to us as individual or as a collective, in the way we live and work. Values are the pillars of the Lived Experience workforce and inform Lived Experience practice<sup>121</sup>. Lived Experience work is distinguished not so much by what Lived Experience workers do but how they do it. The how is guided by Lived Experience work principles and values.

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<sup>118</sup> American Psychological Association Dictionary of Psychology <https://dictionary.apa.org/self>

<sup>119</sup> Gee, G., Dudgeon, P., Schultz, C., Hart, A., & Kelly, K. (2014). Social and Emotional Wellbeing and Mental Health: An Aboriginal Perspective. In P. Dudgeon, M. Milroy, & R. Walker. (Eds.), *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice – Revised Edition* (p.55-68). Canberra: Commonwealth of Australia. <https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/working-together-second-edition/wt-part-1-chapt-4-final.pdf>

<sup>120</sup> Australian Human rights Commission <https://humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/self-determination>

<sup>121</sup> Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., Darwin, L., Castles, C., Craze, L., Saunders, M. National Lived experience Workforce Guidelines. 2021, National Mental Health Commission

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# About LELAN

LELAN is the peak body in South Australia *by, for and with* people with lived experience of mental distress, social issues or injustice. Our purpose is to amplify the voice, influence and leadership of people with lived experience to drive systemic change. LELAN has led philanthropic, state and federally funded projects as well as completed commissioned pieces of work.

LELAN's systemic advocacy targets the mental health and social sectors in South Australia, whilst our thought leadership and expertise on lived experience expertise and leadership is borderless.

By centring the experiences, collective insights and solution ideas of people with lived experience in all of our work, as well as being immersed in the lived experience community from grassroots to strategic and governance levels, LELAN demonstrates the principles, practices and change dynamics that the social sector is calling for and desperately needs. Because of our strong and trusted relationships with people in the lived experience community we are able to have deeper conversations about things that matter, drawing our collective experiences and action together in purposeful ways.

LELAN has extensive experience and a proven methodology for leading lived experience-led and/or co-creation initiatives, frequently with a focus on sensitive issues and including groups that bring divergent perspectives to the conversation. The organisation has three external facing strategic pillars:

- Developing the capability and influence of people with lived experience.
- Nurturing organisational and sector capacity for partnering with people with lived experience, and
- Impacting system improvement agendas to benefit people with lived experience.

LELAN was founded in 2017. The organisation received its first funding in 2019, the result of which led to the launch of *A Roadmap for Strengthening Lived Experience Leadership for Transformative Systems Change in South Australia* and the groundbreaking *Model of Lived experience Leadership* in 2021 (both can be accessed at [www.lelan.org.au/alel](http://www.lelan.org.au/alel)).

## Team for this piece of work

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