

**ACCESS**  
Health & Community

# Access Health and Community

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## Lived and Living Experience Framework

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September 2023



# Foreword

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Access Health and Community's Lived and Living Experience Framework sets out our commitment to continuing to build a thriving Lived and Living Experience workforce.

For over 150 years, Access Health and Community (AccessHC) has engaged deeply with our communities and partnered with them to deliver services that achieve better health and wellbeing outcomes for all.

Our Lived and Living Experience Framework builds on that community engagement approach, recognising the unique perspectives, expertise and skills that those with lived and living experience bring to developing, delivering and leading our work.

Over the last decade, AccessHC has embedded best-practice approaches to lived and living experience within our services, particularly our mental health and alcohol and other drug services.

We have built a workforce of exceptional peer workers, who bring their own experiences and specialist skills to build connections, offer hope and walk alongside our clients in their journey. AccessHC recognises the rich experience peer workers bring to our organisation and thanks them for their continued leadership, including the development of this Framework.

The Framework sets out our commitments and actions to growing, developing and supporting our peer workforce and leaders, both within our mental health and alcohol and other drug services and more generally across AccessHC.

Delivering on this requires deep leadership at all levels, and a strong supporting culture. This is why our Framework embeds Lived and Living Experience awareness as a core competency for everyone at AccessHC, alongside mechanisms for elevating lived and living experience voices at all levels.

Importantly, we recognise that every person has lived experience that influences their views and work, even when they are not employed in a designated lived or living experience role. AccessHC is committed to fostering a culture that recognises the diversity of lived and living experience across our workforce and community, including in people who are not sharing or using their lived or living experience in a designated role.

We are excited to build on these strong foundations to deliver on our commitments over the coming years.



Anna Robinson  
Chief Executive Officer



# Acknowledgements

Access Health and Community (AccessHC) acknowledges the Wurundjeri Woi-wurrung people, who are the Traditional Owners of the land on which we work. We pay our respects to Wurundjeri Elders past and present and future, and extend that respect to all Aboriginal and Torres Strait Islander people. We acknowledge that sovereignty was never ceded.

AccessHC values the unique and important contribution of people with lived/living experience as consumers, family or carers to the development, delivery and improvement of health services. We recognise the wisdom and strength of these voices, and celebrate the rich diversity of the community, our workforce, and the people we provide services to.

This Framework was developed by Elia Baressi (AccessHC Senior Lived/Living Experience Consultant) with support from Lara Anderson (Lived Experience Advisor) and our Lived/Living Experience workforce. Special thanks to Sarah Corkran (Program Support Officer) for her help in collating and editing the final version.

We would like to take a special moment to honour our friend and colleague Joe, whose contributions towards this work were of great significance. Joe was extremely passionate about breaking down barriers in the lived experience space and was a strong advocate for the lived experience workforce. This poem was chosen to honour Joe's wishes for the growth of alcohol and other drug (AOD) and mental health Lived/Living Experience workforce and to represent his existence in our world.

When great trees fall, rocks on distant hills shudder,  
 lions hunker down in tall grasses, and even elephants lumber after safety.  
 When great trees fall in forests, small things recoil into silence,  
 their senses eroded beyond fear.  
 When great souls die, the air around us becomes light, rare, sterile.  
 We breathe, briefly. Our eyes, briefly, see with a hurtful clarity.  
 Our memory, suddenly sharpened, examines, gnaws on kind words unsaid, promised walks never taken.  
 Great souls die and our reality, bound to them, takes leave of us.  
 Our souls, dependent upon their nurture, now shrink, wizened.  
 Our minds, formed and informed by the irradiance, fall away.  
 We are not so much maddened as reduced to the unutterable ignorance of dark, cold caves.  
 And when great souls die, after a period peace blooms, slowly and always irregularly.  
 Spaces fill with a kind of soothing electric vibration.  
 Our senses, restored, never to be the same, whisper to us.  
 They existed. They existed.  
 We can be. Be and be better. For they existed.

*'When Great Trees Fall'*  
 Maya Angelou



# Glossary

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**Lived/Living Experience<sup>1</sup>**

A person with personal 'lived' (past) or 'living' (current) experience of a particular experience or condition. The lived/living experience could be in one or many areas which include, but are not limited to: mental health concerns, alcohol or other drug use, chronic illness or disability, being a refugee, racism, incarceration, family violence, homelessness, dementia, parenting, neurodiversity, or other health conditions or life experiences.

**Consumer Lived/Living Experience**

A person with lived/living experience of the condition or experience themselves.

**Family/Carer Lived/Living Experience**

A person who has lived/living experience as a carer or family member of someone with a particular condition or experience.

**Designated Lived/Living Experience Role**

A position in which the person is intentionally, purposefully and directly using their Lived/Living Experience in their work; Lived/Living Experience is a key selection criteria for these roles.

**Consumer or Carer Consultant**

A designated Lived/Living Experience role in which a consumer or carer shares their perspectives, provides advocacy for consumers/carers and offers insight to help with decision-making and service delivery.

**Community Engagement**

A process whereby we seek out and consider the ideas, views, and aspirations of our community, and use this input to reflect on, develop, and improve our programs and services.

**Intersectionality**

Refers to the ways in which different aspects of a person's identity can expose them to overlapping forms of discrimination and marginalisation.

The concept of intersectionality recognises that people's lives are shaped by their identities, relationships and social factors. These combine to create intersecting forms of privilege and oppression depending on a person's context and existing power structures such as patriarchy, ableism, colonialism, imperialism, homophobia and racism.

**Trauma-Informed Care**

An approach to care that acknowledges a significant number of people have experienced trauma in their lives—which may impact how a person experiences and presents to services. The key aim of trauma-informed care is not to re-traumatise people through engaging in the service and to ensure that the service is welcoming and safe for all, irrespective of a person's trauma history. The core principles of trauma-informed care include safety, trustworthiness, respect, collaboration, choice and empowerment.

**Recovery-Oriented Practice**

An approach to healthcare that emphasises each person's personal journey of healing and values their unique experiences and perspectives. Recovery-oriented practice is based on the view that healthcare services have a role in creating an environment that supports, and does not interfere with people's recovery efforts. This approach moves away from a primarily biomedical view of health to a holistic approach to wellbeing that builds on individual strengths.

**Recovery-Oriented Language**

Language that aligns with recovery-oriented practice and promotes hope, empowerment, and strengths of those in recovery. Recovery-oriented language avoids stigmatising labels and terms, and focuses on the whole person rather than only their illness/experiences.

**Intentional Peer Support (IPS)**

A model of peer support work that involves thinking about and inviting transformative relationships. Practitioners of IPS learn to use relationships to see things from new angles, develop greater awareness of personal and relational patterns, and support and challenge each other in trying new things. IPS relationships are viewed as partnerships, promote a trauma-informed way of relating, and encourage people to live and move towards what they want/need instead of focusing on what they need to stop/avoid doing.

**Social and Emotional Wellbeing (SEWB)**

A term used by many Aboriginal and Torres Strait Islander people to describe the social, emotional, spiritual and cultural wellbeing of a person. The term recognises their connection to land, sea, culture, spirituality, family and community, which are important to people and impact on their wellbeing.

**Stigma**

When someone is seen in a negative way because of a certain characteristic or attribute e.g. mental illness, substance use history, skin colour, cultural background, or disability. Stigma can lead to discrimination and poorer health outcomes.

**Dignity of Risk**

A recovery-oriented approach which involves promoting people's choice, agency and self-management and recognises that people can make decisions which are associated with a degree of risk. This involves working with the inherent tension between encouraging 'positive risk taking' and promoting safety (Department of Health, 2007).

**IPA2 Spectrum**

The [IAP2 Spectrum](#) is a tool designed to assist with the selection of the level of participation that defines the public's role in any community engagement program. The Spectrum outlines differing levels of participation (inform, consult, involve, collaborate and empower) depending on the goals, timeframes, resources and levels of concern in the decision to be made.

**Mutuality**

A concept detailed in the Intentional Peer Support model. Mutuality examines our lives in the context of mutually accountable relationships and communities; looking beyond the mere notion of individual responsibility for change.

**Imbalance of Power**

Refers to the notion that there is often an inherent power imbalance between people with lived/living experience (including family and carers) and other key stakeholders including clinicians, management, policy makers and funding bodies. This imbalance of power can be expressed through language, autonomy, actions and restrictions and can result in people with lived/living experience feeling excluded, ignored or distressed.

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<sup>1</sup> The term 'Lived/Living Experience' when referring to roles or the workforce, is capitalised to distinguish the professional from the personal, i.e. working in a Lived/Living Experience role as opposed to 'having a lived experience'.

# Introduction

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Access Health and Community (AccessHC) is committed to growing and supporting our Lived/Living Experience workforce. We're also committed to embedding Lived/Living Experience in governance and leadership throughout our organisation, and consulting, collaborating and empowering people with lived/living experience to ensure that our services meet the needs of the communities we work in.

For nearly ten years, AccessHC has employed a Lived/Living Experience workforce across mental health, alcohol and other drug (AOD) and community services—and we are proud of the important role that peer support workers have played in our multi-disciplinary approach to caring for the community. We believe that Lived/Living Experience roles are central to achieving our purpose of building “healthier lives together”.

AccessHC is now taking the next steps in our lived/living experience journey to expand on this existing work and develop a Lived and Living Experience Framework that is relevant across our whole organisation. The purpose of this Framework is to support understanding and best practice in engaging, employing, and working with people who have lived/living experience across all areas within AccessHC. In some areas, this will be an expansion of existing work; in others, it will be the introduction or development of new work.

By creating this Framework, we hope to support a culture of commitment and readiness to implement the principles we mention throughout. This will allow us to better support all consumers, carers, and families that receive services from AccessHC.

Our hope is that this document will be a collaborative and innovative collection of ideas, co-design, education, and planning. This Framework has attempted to capture the values, themes, strategies, and vision of the Lived/Living Experience work currently being undertaken at AccessHC, while also planning for future workforce growth and development.

Developed and written by our Senior Lived Experience Consultant in consultation with a Lived/Living Experience Reference Group, practitioners, staff, Senior Leadership, Executive and Board, the Framework aims to guide best practice and ensure that people with lived/living experience are recognised and supported to thrive at all levels of our organisation.

We would like to acknowledge the many pieces of work and contributions that have been collated to create this framework.

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**“The core theme identified through the national consultation process was the need to develop flexible, recovery-oriented workplaces where Lived Experience workers are enabled to achieve in their professional roles with flow-on benefits for the whole workforce and for service users and their families.”**

– National Lived Experience (Peer) Workforce Development Guidelines, 2021



# Framework Consultation – Key Learnings

In 2022, a number of Lived/Living Experience staff and other internal and external stakeholders were consulted throughout the process of developing this Framework. A Lived/Living Experience Reference Group comprising peer support workers from AccessHC and partner agencies was also established to provide guidance and input. We also reviewed published guidelines, frameworks and strategies relating to Lived and Living Experience.

A visual summary of the sources of information and consultation used to develop this Framework are represented below.



Figure one: Visual summary of the sources of information

Key learnings from the consultation about our existing Lived/Living Experience workforce and service delivery at AccessHC are summarised below:

<b>What is working well?</b>	<b>What needs improvement?</b>
Lots of autonomy within each Lived/Living Experience program area	Role clarity for individuals in Lived/Living Experience roles and how this fits with other disciplines/teams
Most staff are open to Lived/Living Experience feedback	Support to develop individual strengths into Lived/Living Experience work
People understand the value Lived/Living Experience workers bring	Currently (in 2022) there are limited options within the organisation for Lived/Living Experience career progression
Level of trust between Lived/Living Experience workers and management that isn't always present in other organisations	More flexible working arrangements given the nature of Lived/Living Experience work and the toll it can take
Lived/living experience is encouraged and utilised in some areas of our organisation	More streamlined processes across teams and programs (such as referral processes and risk escalation) are needed
Sense of solidarity among Lived/Living Experience workers	More workshops and educational opportunities for non Lived/Living Experience staff, delivered by Lived/Living Experience workers
AccessHC leadership are open to Lived/Living Experience feedback and input	Senior Lived/Living Experience staff needed to assist navigation of the organisation and systems we work in, provide guidance to all Lived/Living Experience workers
Lots of opportunities among Lived/Living Experience workers to debrief	More education for non-Lived/Living Experience staff to understand the principles of Intentional Peer Support, boundaries of Lived/Living Experience work and remove myths/perceptions e.g. that peer workers are no different to friends.



# Importance and Benefits of Lived/Living Experience in an Organisation

The value that lived/living experience brings to services and organisations is vast. As illustrated below, there are benefits for:

- People accessing services
- People working within the services
- The organisation as a whole

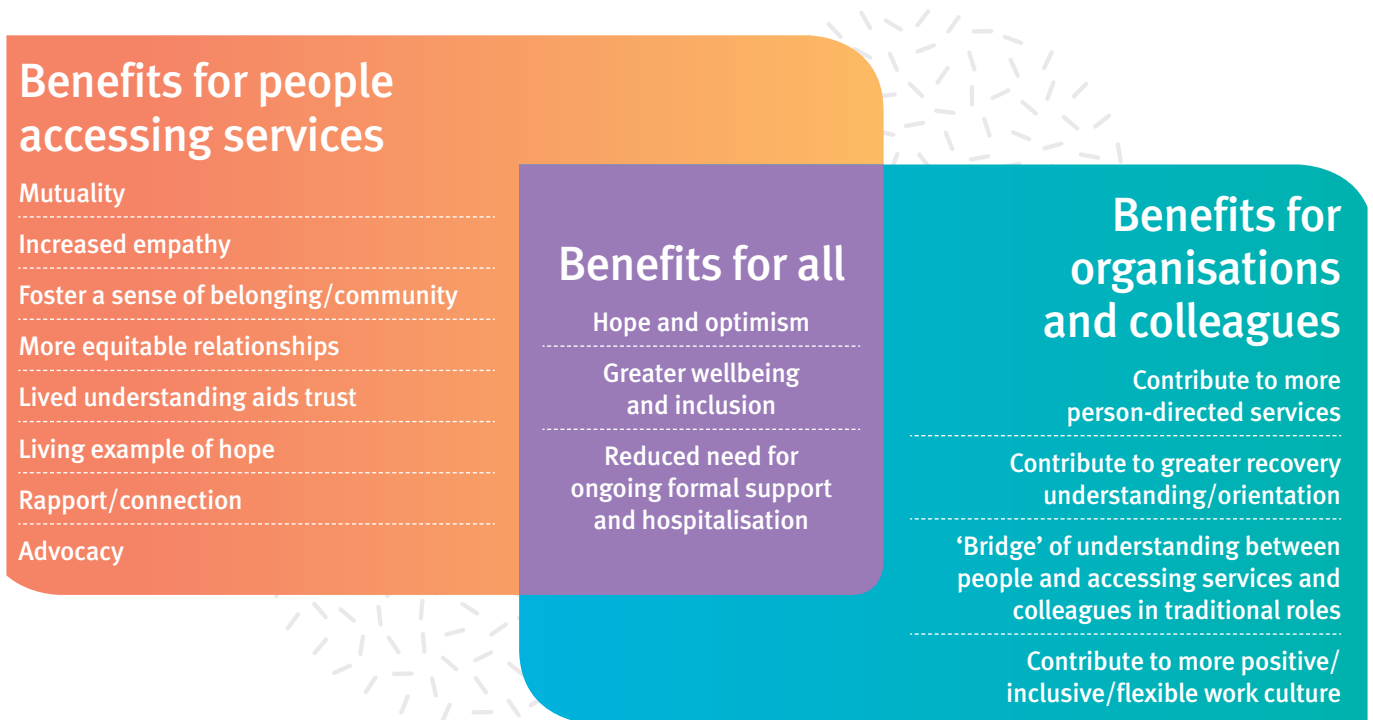


Figure Two. Image credit: Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., Darwin, L. [Queensland Framework for the Development of the Mental Health Lived Experience Workforce](#). 2019, Queensland Government: Brisbane

The table below from Lived Experience Leadership outlines some of the factors which make Lived/Living Experience roles effective, and the importance of having these positions within healthcare services.

**What makes Lived Experience roles effective?**

Lived expertise, not just having a lived/living experience but what has been intentionally learned through that experience and how it’s applied to benefit others	Links with and understanding of the wider Lived Experience community and concepts including Lived Experience-led research/training
Work that is values-based and authentically Lived Experience informed, person-directed and aligned with recovery principles	Significant understanding and ability to use personal story effectively and appropriately for the benefit of the person accessing services
Being an advocate/change agent	A focus on human rights and systems change
Greater flexibility and ability to be responsive to the person accessing services	Show that recovery is possible and it’s not a linear journey — it’s natural to have ups and downs and that’s okay
A bridge between organisations and people accessing services/supporting people accessing services	Trauma-informed: awareness of the role and impact of trauma and wish to respond compassionately and sensitively
Ability to challenge power imbalances and provide more equity in support	Strengths-based, focused on the relationship/person
Willingness to potentially face discrimination/negative attitudes as a result of being ‘out’ about their experiences	

Figure Three. Image credit: Lived Experience Leadership, ‘Understanding and Defining the Roles’, 2023.

**Why do we need a Lived/Living Experience Framework?**

Lived/Living Experience workers provide a platform for social change. As diverse change agents, it’s essential that organisational values align with and support principles of Lived/Living Experience. AccessHC’s organisational values of *Collaboration, Innovation, Respect, Equity, and Quality* underpin our Lived and Living Experience Framework.

A core component of this alignment is having a well-established and well-supported workforce with dedicated roles, supports, and opportunities for people with lived/ living experience.

By embedding the principles of Lived/Living Experience across the organisation, it is our aim that these disciplines are firmly embedded into the delivery of services across AccessHC.

Our ultimate goal is well-established service systems with an organisational commitment to change and co-design.

The aims of this Framework are to develop and embed:

- A shared understanding and commitment to Lived/Living Experience across AccessHC
- A thriving and well-supported Lived/Living Experience workforce
- Opportunities for development and career progression in our Lived/Living Experience workforce
- Integrated Lived/Living Experience work across different programs and areas at AccessHC
- Lived/Living Experience governance and leadership positions and capability across the organisation
- Lived/Living Experience voices which are heard and respected at all levels, including in governance and leadership
- A culture in which Lived/Living Experience of diverse life experiences and health conditions are valued for their unique perspective and positive impact on health outcomes.

# Stigma and the Use of Language

**‘When we communicate with, for, and about people with disabilities, diseases, and health conditions, it’s important to learn the history of their experiences with social stigma and prejudice. One of the most effective ways of doing this is to listen to the self-advocacy groups in these communities; this will ensure that our language choices are respectful, inclusive, and supportive.’**

– Shannon Wooldridge, Public Affairs Specialist, NIH Office of Communications and Public Liaison

When discussing Lived/Living Experience, it is important to acknowledge the role of language, stigma, and how using particular language has the potential to cause harm or perpetuate stigma.

Stigma prevents people from seeking the help they need and is a barrier to engage with health services, particularly for ‘hardly reached’ communities. These experiences can make someone feel like they’re not welcome, or undeserving of support. It may also cause someone to disengage from support with health services.

A core concept to consider is the difference between person-first or identity-first language.

**‘Person-first language is a way to emphasize the person and view the disorder, disease, condition, or disability as only one part of the whole person. Describe what the person “has” rather than what the person “is”... Some communities, however, prefer identity-first language because they consider some characteristics as inseparable parts of their identity. Those who prefer identity-first language consider it a way to show pride in who they are and their membership in a community.’**

– National Institute of Health Style Manual

Someone with a mental health condition may prefer to use **person-first language** e.g. a person with bipolar disorder. Person-first language is also often preferred in relation to substance use (e.g. a ‘person who uses drugs’ instead of ‘drug user’ or ‘drug addict’). Similarly, you may refer to a ‘person seeking asylum’ rather than ‘an asylum seeker’.

**Identity-first language**, however, can be an important part of demonstrating pride in a particular identity or acknowledgement as a member of a particular community e.g. an autistic person or First Nations person. Some people will also identify as being an ‘addict’ or ‘in recovery’ as a way of connecting with a community of people with similar lived experiences. Ultimately, **we should always be guided by the person we’re engaging with**, and their own experiences and language preferences.

From a public health perspective, language can also defer responsibility onto an individual and away from broader societal issues and competing interests, which can create stigma. It’s also important to remember that seemingly innocuous comments, words, and labels have the potential to perpetuate stigma and cause harm. Throwaway phrases like “I’m so OCD” (because you like your desk clean), or “this week has been crazy” (to describe a busy or stressful week) can be hurtful to people with lived/living experience and serve to further perpetuate stigma, shame and discrimination.

## Lived/Living Experience as the preferred term

The *National Lived Experience (Peer) Workforce Development Guidelines* note a preference for using the term ‘lived/living experience’ as the overarching term because it’s inclusive of both personal (consumer) and family/carer roles.

The Guidelines note that an alternate title of ‘peer workforce’ is often misunderstood as referring only to direct peer support work, and was not commonly understood as inclusive of other types of designated work (e.g. positions focused on policy, education, strategy or research). For this reason, our Framework refers to the Lived/Living Experience workforce, which includes (but is not limited to) peer support workers.

## Need for culturally appropriate and inclusive terminology and concepts

The *National Lived Experience (Peer) Workforce Development Guidelines* also acknowledge the importance of using culturally appropriate terminology and language.

Aboriginal and Torres Strait Islander Peoples, as well as many people from non-Western cultures, have differing concepts of health from the mainstream service system and may place greater significance on the role of kinship, interconnectedness and spirituality. These differences

are often demonstrated using alternate terms, including 'spiritual imbalance', 'social and emotional wellbeing', and 'strong spirit' in understanding experiences.

'Stigma' as a term, also lacks relevance for different cultures. For example, for Aboriginal and Torres Strait Islander Peoples, stigma is not seen as culturally appropriate. Instead the term 'shame' is accepted as culturally significant, important and different from stigma.



# Lived/Living Experience Roles within Healthcare

"Lived Experience roles exist in diverse organisations and settings, spanning entry level to executive leadership roles. While it's true that everyone has some experiences of distress and adversity, not everyone has significant challenges that take their lives in an entirely new direction. Lived Experience roles are primarily informed by life changing challenges and experiences."

– Lived Experience Leadership, 'Understanding and Defining the Roles', 2023

## What is a Designated Lived/Living Experience role?

People with lived/living experience<sup>1</sup> have had significant personal experiences with a particular health condition or life experience, or are a family member or carer of someone who has had those experiences. This might include (but is not limited to) experiences of: mental health issues, substance use, chronic illness or disability, being a refugee, incarceration, family violence, homelessness, dementia, parenting, neurodiversity, or other health conditions or life experiences. They may have significant experience accessing (or trying to access) services, and varying experiences of recovery, acceptance, and healing.

Designated Lived/Living Experience roles require lived/living experience as part of the key selection criteria, and require the person to intentionally and purposefully use their lived/living experience as part of their day-to-day work. For this reason, designated Lived/Living Experience roles are often described as "bringing your whole self to work".

Members of the designated Lived/Living Experience workforce can work in a range of positions across various settings, including:

- consumer peer support work
- family/carer peer support work
- Lived/Living Experience Consultant positions
- Lived/Living Experience management and leadership roles
- consultation, reference groups and advisory committees (including Board)
- provision of Lived/Living Experience supervision, education and training
- Lived/Living Experience roles in policy and government.

Although designated Lived/Living Experience roles are relatively new in comparison to other disciplines in healthcare, there has been significant growth in Lived/Living Experience roles in recent years. As an example, the Victorian Department of Health now has an Executive Director of Lived Experience who leads the Lived Experience Branch within the Mental Health and Wellbeing Division.

Many people with lived/living experience are not employed in designated roles and therefore don't use their lived/living experiences directly in their work. AccessHC is welcoming of people with diverse experiences and identities and we know many of our people will have a lived/living experience in areas such as mental health, substance use, chronic illness, disability, parenting, neurodiversity or other life experiences. We welcome, respect and value the richness of these experiences among our people, and support an organisational culture in which everyone's lived/living experience is welcomed and respected. However, while these experiences inevitably inform our perspective on life, core values and motivation, there is no expectation or requirement for people to share these experiences within their roles at AccessHC. It is important to recognise that there is specific training, qualifications and supervision that Lived/Living Experience workers receive to ensure that they can share their Lived/Living Experience in a way which is safe, meaningful and effective.

<sup>1</sup> The term 'Lived/Living Experience' when referring to roles or the workforce, is capitalised to distinguish the professional from the personal, i.e. working in a Lived/Living Experience role as opposed to 'having a lived experience'.

### Intersectionality and Lived/Living Experience

It's important to consider intersectionality and how this can impact people with lived/living experience. Intersectionality refers to the ways in which different aspects of a person's identity can expose them to overlapping forms of discrimination and marginalisation. For example, someone may have more than one type of lived/living experience. This could look like someone:

- with a mental illness who is also a carer of someone with a mental illness or disability
- who has experiences of being incarcerated who is also chronically ill
- who is transgender and who is also a parent.

Intersectionality can also include other social characteristics and membership of particular communities, e.g. Aboriginal and Torres Strait Islander peoples, LGBTQIA+ people, people from Culturally and Linguistically Diverse (CALD) backgrounds, and other cultural experiences.

For people with lived/living experience, intersectionality is a common experience and can sometimes add complexities to receiving care, or increase experiences of marginalisation/discrimination. It's important to be aware of how someone's identity/identities can impact their health and wellbeing.

### Consumer and Family/Carer Lived/Living Experience roles

Broadly, the Lived/Living Experience workforce includes **consumer** Lived/Living Experience roles (positions which focus on the person's own lived experience of a particular condition or experience) and **family/carers** Lived/Living Experience roles (positions which focus on the person's experience as a family or carer of someone with a particular condition). Some people will have a lived/living experience as both a consumer and a family/carers and may be employed in positions relating to one or both experiences.

### What is a Peer Support Worker?

"[Peer Support Workers] understand the critical need for connection and utilize this expertise to inspire others to find hope. They build relationships based on a collective understanding of shared experience, self-determination, and empowerment, and they provide an important resource for change."

– National Mental Health Commission, 2023

**A peer support worker is a designated Lived/Living Experience role, in which the person intentionally and purposefully uses their own lived/living experience to provide emotional and practical support to others. This includes both consumer peer workers and family/carers peer workers.**

Everyone's journey is unique, and there is no one way to approach peer work. It's important that all individual experiences are valued, and this informs how peer support workers work with the community. Peer support work is often described as "walking alongside someone in their journey". Unlike many clinical services, peer work is not about providing advice or telling someone what they should do or how they should behave. A peer support worker is neither a friend or a clinician, and brings a unique perspective to a person's care within the health system.

Some of the key components of peer support work include:

- providing social connection and support through a Lived/Living Experience lens
- creating a safe environment for consumers and families
- assisting with connection to resources and services
- experiential sharing and relationship building
- goal setting, skill building, and mentoring
- increasing self-esteem and self-efficacy
- offering hope, empathy and connection from a Lived/Living Experience perspective.

A key aspect of peer support work is the use of 'purposeful disclosure'. This is one of the key training requirements for a peer support worker to ensure that sharing their own Lived/Living Experience is done in a safe and effective way. Below are some reflective questions a Peer Support Worker may consider when deciding to share their own lived experience with someone they are working with:

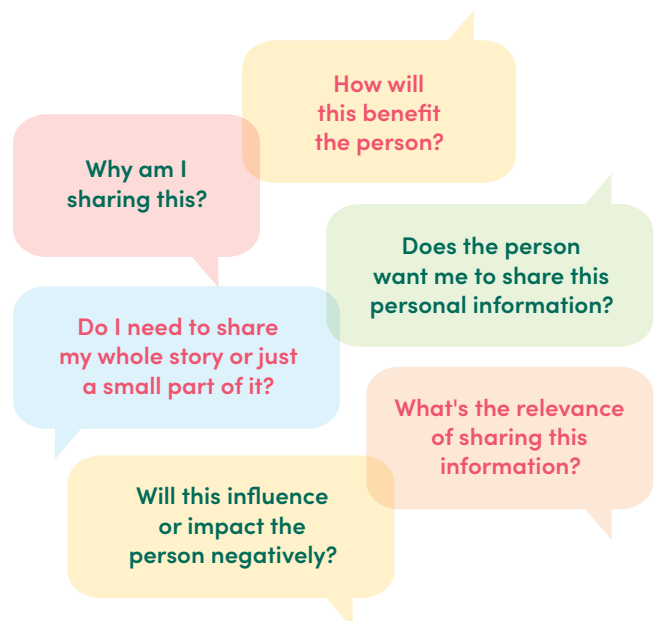


Figure four: Reflective questions to guide purposeful disclosure



# Engaging with People with Lived/Living Experience

Access Health and Community is committed to engaging with and hearing the voices of the communities we work in as outlined in our [Community Engagement Framework](#).

Community engagement is a process whereby we seek out and consider the ideas, views, and aspirations of our community (consumers, carers, local community members, and our workforce) —and use this input to reflect on, develop, and improve our programs and services. Some methods of engagement could include reference groups, surveys, and co-design workshops.

It is likely that we will invite community to intentionally share their lived/living experiences as part of this engagement to inform decisions that the organisation makes. In these instances, we will use the Lived/Living Experience and Community Engagement Frameworks together to inform our practice. For example, by conducting a co-design workshop with people who have lived/living experience of diabetes in the development of a new diabetes program/service.

## Safe and meaningful engagement with people with Lived/Living Experience

Many people have experienced a significant loss of power in their lived/living experiences. This is particularly true for people who have been subject to compulsory or invasive treatment in health, or have experienced incarceration or restricted freedoms (such as prison or detention centres). It is also particularly relevant for Aboriginal and Torres Strait Islander Peoples who have been impacted by colonisation and intergenerational trauma.

It is important to be aware of any potential power imbalances and actively work to re-balance power between people with Lived/Living Experience and other members of the organisation or engagement team, including (but not limited to): clinicians, managers, policy makers and funding bodies. Following co-production and co-design principles will assist in the rebalancing of power in these situations.

Other key principles for effective engagement with people who have Lived/Living Experience include:

- creating a safe space (physically, spiritually and emotionally) - this may include using trauma-informed spaces and providing 'content warnings' before discussing topics that may be distressing to participants

- offering clinical or peer support to participants before, during and after engagement (including an opportunity to debrief)
- using plain English and ensuring all communication follows health literacy principles
- ensuring that expectations and requirements of the engagement are clear at the outset of the engagement and understood by all participants.

It's also important to be conscious of 'consultation fatigue', particularly when engaging with people with very specific Lived/Living Experiences who may be frequently and repeatedly approached to share their experiences or participate in consultations and engagement activities.

In line with our [Community Engagement Framework](#), AccessHC is committed to providing a 'feedback loop' to people who participate in community engagement, including reasons for why particular feedback may not have been actioned or adopted.

*"One of my most memorable moments as a consumer peer support worker, was being asked to join a lived experience research group to review some of our current mental health programs which would go on to become a published evaluation. Part of this process was consultation with other staff, past consumers, carers, and families. One of the first meetings I attended, I was the only person there who was not in a senior or leadership clinical role - I immediately became very nervous about what to share about my story and how much to share. To begin, we were told there was no pressure to share if we didn't feel comfortable, however, when we went around the table to introduce our roles, each of the clinicians gave a really honest and raw reflection on why they were in the group and why it was important to them. People in senior leadership and management shared their bereavement of suicide, their caring for a loved one who had attempted suicide, and more. It was a game changer, and when it came to my turn, I felt no hesitation to share my own, and very personal, reasons for being there. It was a moment that the power imbalances were gone, no one was above or below anyone, we all had a common connection and that connection was a foundation for amazing work."*

– Elia, Peer Support Worker

### Lived/Living Experience Advisory Groups and Reference Groups

An important mechanism to engage with people with lived/living experience and support Lived/Living Experience governance is to have designated Lived/Living Experience representation on organisational committees, and on reference groups and advisory groups.

As with other forms of engagement, it is vital that establishing Lived/Living Experience reference groups and inviting Lived/Living Experience members on organisational committees is done in a safe, considered and meaningful way. This includes, but is not limited to:

- establishing an organisational culture where Lived/Living Experience is understood, valued and accepted
- articulating clear aims and Terms of Reference for committees and reference/advisory groups
- providing appropriate induction, training, resourcing and support for committee members which includes explanation of Lived/Living Experience roles
- ensuring that consumer/carer members of committees are treated with respect and as equal members of the committee.

AccessHC currently has a number of Lived/Living Experience advisory and reference groups, and seeks to grow and expand this area of Lived/Living Experience governance with the implementation of this Framework.





## Our Commitments

AccessHC is committed to supporting a thriving Lived/Living Experience workforce and ensuring that the voices of people with lived/living experience are heard and respected at all levels of our organisation. Our Lived/Living Experience Framework outlines three core commitments:



These commitments will form the basis of our Lived/Living Experience Framework Implementation Plan and are outlined in more detail below.

# 1 Strong organisational culture and commitment to Lived/Living Experience



- a. Commit to person-directed, trauma-informed service delivery across our organisation which values a Lived/Living Experience perspective
- b. Lived/Living Experience is a key element within the AccessHC Service Model
- c. A 'Recognition of Lived/Living Experience' statement is used in relevant meetings and forums
- d. Our commitment to Lived/Living Experience is visible on our website and in other accessible formats for the community
- e. Organisational leaders (including our Board, Executive and Senior Leaders) will be trained in Lived/Living Experience to foster mutual understanding and respect.

# 2 A thriving Lived/Living Experience workforce



- a. Key workforce principles from the [National Lived Experience \(Peer\) Workforce Guidelines](#) are adopted to support a thriving Lived/Living Experience workforce at AccessHC
- b. Appropriate training and consumer/carer perspective supervision is provided for all members of the AccessHC Lived/Living Experience workforce
- c. Create impactful Lived/Living Experience leadership positions that are able to support and guide development of our wider Lived/Living Experience workforce and maintain the integrity of Lived/Living Experience roles
- d. Explore development and expansion of peer support worker roles across different services at AccessHC (such as in family, allied health or child and family programs).

# 3 Lived/Living Experience governance and engagement



- a. Develop processes to safely introduce designated Lived/Living Experience positions within relevant organisational and Board committees
- b. Develop Lived/Living Experience reference/advisory groups to provide a mechanism for people with lived/living experience to influence service design, delivery and evaluation
- c. Support safe, meaningful and effective engagement with people with lived/living experience through use of the [AccessHC Community Engagement Framework](#) and Lived/Living Experience Framework.

# Resources and Further Information

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## Peer Workforce Guidelines

The [National Lived Experience \(Peer\) Workforce Development Guidelines \(National Mental Health Commission, 2021\)](#) are comprehensive guidelines to support the mental health lived experience workforce in Australia. The guidelines include:

- [Lived Experience Roles: A Practical Guide to Designing and Developing Lived Experience Positions](#)

The [Strategy for the Alcohol and Other Drug Peer Workforce in Victoria \(2019\)](#) was published by SHARC to support the AOD peer workforce in Victoria.

## Language and Stigma

[The Power of Words \(Alcohol and Drug Foundation\)](#) is a comprehensive resource outlining the importance of language and stigma in relation to alcohol and other drug use. It includes a number of practice guides:

- [Having Alcohol and Other Drug Conversations: A Practical Guide](#)
- [The Power of Words: Background Document](#)

## Consumer Engagement and Governance

The [Health Issues Centre](#) provides a range of resources to support the safe and effective participation in organisational committees by consumers and family/carers within health services.

- [Guide to Engaging Diverse Consumers in Organisational and Governance Structures](#)
- [Getting Started: Involving Consumers on Health Service Committees](#)
- [Guidelines for Consumer Representatives: Suggestions for Consumer or Community Representatives Working on Committees](#)

## Lived/Living Experience Peak Bodies

There are a range of organisations and peak bodies for people with Lived/Living Experience, including:

- [Association of Participating Service Users \(APSU\)](#) – Victorian peak body for people who use, have used, or are eligible to use alcohol and other drug services
- [Australian Injecting and Illicit Drug Users League \(AIVL\)](#) – Australian peak body for people who use or inject drugs, representing State and Territory peer-based drug user organisations
- [Carer Lived Experience Workforce \(CLEW\) Network](#) – Network of Family/Carer Peer Workers in Victoria
- [Health Issues Centre](#) – Victorian peak body for health consumers
- [Self Help Addiction Resource Centre \(SHARC\)](#) – lived experience-led organisation providing support, training and supervision for the alcohol and other drug peer workforce in Victoria
- [Lived Experience Leadership](#) – supporting Lived/Living Experience research and workforce development
- [Tandem](#) – Victorian peak body representing families and carers of people with mental health issues.
- [Victorian Mental Illness Awareness Council \(VMIAC\)](#) – Victorian peak body for people with a lived experience of mental health problems or emotional distress.





**Building healthier lives together**

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