

Lived and living experience:

Strengthening services in the alcohol and other drugs sector

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In Australia, people with lived and living experience (LLE) of alcohol and other drugs (AOD) play an important role in the AOD sector.

And they have for decades. From the establishment of volunteer peer support groups like Alcoholics Anonymous (AA) in the 1940s, to grassroots peer-led harm reduction and education initiatives in the '60s, and the needle and syringe programs in response to HIV in the '80s.¹⁻³

LLE involvement continues to expand and is now present in most Australian AOD settings, including withdrawal, rehabilitation, harm reduction, hospitals, and community health.

Its importance has been re-enforced by the establishment of a dedicated Lived Experience Branch within the Victorian Department of Health in 2021.⁴

Increasingly, there is widespread support for meaningful and ongoing LLE involvement across all levels of health and social supports, including:

- strategy and policy
- research
- education and training
- leadership and program design
- service delivery.^{5, 6}

In this resource, we explore what LLE is; roles for people with LLE in the Australian AOD sector; how their unique expertise can improve outcomes for everyone; and, the key considerations for involving LLE in your work.

A note on language:

We recognise that words can have different meanings to different people, that language preferences differ across communities and experiences are personally defined.

The language used in this resource has been informed by *The Power of Words*, and in consultation with *Self Help Addiction Resource Centre (SHARC)* and *Harm Reduction Victoria (HRVic)*.

What is lived and living experience?

Lived and living experience (LLE) means a person draws on their current or previous experiences, expertise, skills and insight to benefit others, improve systems and advocate for **human rights**.

These benefits also extend to the community, improving people's access to equal and fair treatment, quality healthcare and support, and protecting their right to dignity and respect.⁵

LLE can be an individual's first-hand experience and/or the experience of supporting someone close to them as a family member, carer or supporter.⁵

LLE in AOD

Lived experience: People with previous personal experiences of alcohol and other drug use and/or dependence (addiction) that has radically changed how they see the world.⁷

Living experience: People with current experiences of alcohol and other drug use.⁸

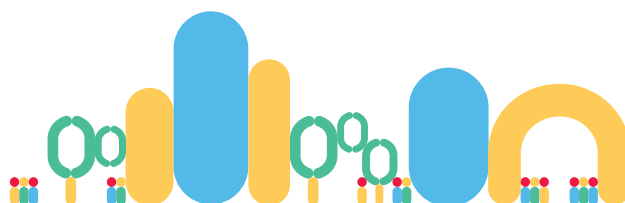
Families, friends, and carers with experience of supporting someone with alcohol and other drug use and dependence, are also included in both these terms.

While LLE roles require a person to have experience with substance use and related harms or supporting someone in these circumstances, it's the expertise, knowledge, skills and wisdom gained through this experience that are critical.

In the AOD sector, across service streams including harm reduction, LLE roles can take many forms.

Roles and titles may vary, but are often divided into two overarching categories:

- LLE workforce
- LLE participation (via consultation, partnership or control).



LLE workforce

Roles can include: peer worker, harm reduction peer worker, consumer consultant/advocate, discipline specific supervisor, family carer peer worker, family carer consultant/advocate, leadership and governance.

The LLE workforce often supports people in treatment, family support and harm reduction settings. They use their LLE expertise, collective community knowledge, practice skills and formal training to deliver services and support.⁹

They play a key role in reducing stigma, increasing person-centred care and bridging the gap between services and the people who use them.⁷

While primarily employed within the AOD sector, alcohol and other drug LLE workers also work in mental health and wellbeing, criminal justice, and acute and community health settings.

Peer workers work directly with people accessing services. They focus on building relationships where self-determined healing is supported through:

- identification (the ability to comfortably identify with their experiences)
- mutuality (sharing with others who also have these experiences)
- connection.⁷

Peer workers walk alongside service users, providing information and advocacy and strengthening services through sharing service user perspectives.⁷

Harm reduction peer workers (HRPWs) are people with a lived or living experience of drug use and risk of overdose. They're employed in harm reduction work to promote the health and wellbeing of people who use drugs.⁸ They have a current connection to the criminalised and stigmatised community of people who use drugs and are accepted as peers by their community.

HRPWs are sometimes called living experience peer workers, but HRPWs may not always identify with this term or feel safe disclosing their drug use due to it being illegal. And, not all identify as having living experience; some have lived experiences.

Family/supporter AOD lived and living experience workers also draw on their life-changing experiences (current and past). They support and advocate for people impacted by substance use and/or dependence through a family or supporter perspective, to minimise experiences of isolation, stigmatisation and marginalisation.¹⁰

The LLE workforce also includes roles outside of direct support services.^{6,9} For example, facilitating education and training sessions, developing policies, collaborating on/or leading research, and leading teams and organisations.¹¹

Designated vs non-designated roles

A **designated role** is where LLE expertise is an essential requirement for the role, in addition to relevant training, skills and knowledge.³ This includes all positions that require LLE as a key criteria, regardless of position type or setting.³

A **non-designated** role is where LLE expertise is not essential to the role.⁷ These roles are often guided by the values and practice guidelines of their profession or discipline, such as a social worker, counsellor or nurse.

The difference between these is important to note. For people in designated LLE roles, their primary lens is their lived and living experience and expertise, which means they apply the LLE values and methods to the work they do.¹²

In Australia, it's estimated that over 40% of AOD workers have LLE, but less than 10% of all AOD workers are in designated roles.³



CONSIDERATIONS FOR EMPLOYING PEOPLE WITH LLE

Recruitment

- Ensure recruitment processes are developed with people with LLE, and there is LLE representation on the interview panel.
- Clearly communicate your organisation's policy and process for criminal background checks in the advertisement and emphasise that a criminal history does not automatically disqualify a person.
- Some people with LLE may have a criminal history related to their LLE. In some cases, this may even be entirely appropriate or essential. For roles where a criminal history check is required, consider the applicant's criminal history on a case-by-case basis.
- Employing multiple people in LLE roles ensures diversity of perspectives and insights. It's recommended that more than one person is employed in a designated LLE role, as being the only person can be isolating and place increased pressure on the LLE worker.
- Provide a consistent contact person to LLE candidates for support throughout the recruitment, onboarding and implementation process. Ideally, someone else with LLE who is also in a designated role.^{13,14}

Workplace conditions

- Ensure pay/award and conditions reflect the value of LLE workers' unique expertise. LLE workers report lower annual gross salary ranges and higher rates of unpaid volunteer work, compared to people without LLE.^{3,15}
 - If unsure, check pay/award and conditions with LLE organisations like HRVic or SHARC, unions or the Fair Work Ombudsman.
- Providing flexibility between full-time, part-time and casual work is important.
- Where possible, provide job security by offering permanent and ongoing contracts.^{13,14}

Workplace culture

- Ensure LLE workers feel valued as an equal part of a multi-disciplinary team by clearly defining LLE roles, acknowledging their unique contributions, and fostering a shared understanding of their importance among staff across all levels/disciplines.
- Create a workplace culture that reduces and eliminates **stigma and discrimination**.
- Encourage non-LLE workers to advocate for integrating LLE – not just LLE workers themselves. By providing organisational readiness training you can ensure all non-LLE workers feel confident in advocating, through increased understanding of the nature of LLE work, the LLE workers' experience and knowledge base and the skills required to work alongside LLE workers.
- Ensure designated LLE representation in senior management, executive and boards. This helps to drive integration of LLE through structural and procedural changes, particularly in multidisciplinary teams where knowledge of LLE work may be limited. Senior management's attitudes are often cited as the most essential ingredient to influencing workplace culture, and the biggest barrier to change.
- Follow best practice – an LLE worker's line manager should also be in a designated role or have had previous experience in one, especially if the LLE worker is a peer worker.^{3,14,16,17}



Role clarity

- Ensure LLE position descriptions are developed in collaboration with people with LLE. Position descriptions need to be clear, well-defined and focus on bringing an LLE perspective to the tasks they perform.
- Ensure all staff are familiar with the relevant **LLE workforce discipline frameworks** and the **National Lived Experience Guidelines**.
- Encourage and provide opportunities for LLE workers to lead or co-design service and operational processes and procedures.
- Value LLE roles and their unique perspectives and expertise, assign tasks relevant to LLE principles and scope of practice.
- Keep in mind the criteria for a role will look different depending on the setting and role specifics. For example, a residential setting may require abstinence from substances, which may not align with the experience or values of some LLE workers.^{13,14}

Measuring success

- Partner with people with LLE to create, regularly review and iterate success measures for their role.
- LLE work in principle is not outcomes focused but often leads to improved outcomes for people using the services. The aim of LLE involvement is better and more meaningful engagement between services and the people who use them.
- Implement diverse success measures to meet the needs of diverse backgrounds. For example, Aboriginal and Torres Strait Islander communities may value measuring how much LLE support addresses social networks, spirituality, or connection to country.
- Include people's experiences as determinants of success. This can be done through feedback from people who use the service, such as if they felt heard and understood, empowered and/or informed.^{13,18}



Supervision

- Provide **internal line-management supervision** for the LLE workforce.
- Also provide and fund **external discipline-specific supervision**, to focus on reflective practice, debriefing, boundaries, role scope, the impact of LLE work, and applying a worker's unique skills. External supervision provides privacy and choice, reduces potential conflicts of interest and role confusion, and may be better at identifying role drift.
- If only internal discipline-specific supervision is available, ensure supervisors have personal experience as an LLE worker and are not their operational or line manager. Internal supervision should only be a last resort option.^{13,14}

Support

- Consult with all employees when creating health and wellbeing policies and procedures to ensure they meet everyone's needs.
- Enable flexibility in procedures to allow for reasonable accommodations tailored to, and developed with, any employee requiring support – LLE and non-LLE alike.
- This is particularly important for those facing multiple marginalisations, such as race, gender, sexuality, class, disability, neurodiversity and criminalisation.
- Peer Projects at SHARC provides training, support and resources for the AOD peer workforce and the organisations that employ them.
- Fuse Initiatives at HRVic provides training, support and resources for the harm reduction peer workforce and the organisations that employ them.^{13,14}

Professional development

- Provide access to, funding, and time for regular LLE specific and non-LLE specific training. Any non-LLE specific training should still uphold the values and/or scope of LLE work. Non-LLE specific training can include general skills such as clinical, communication or technology skills.
- Provide and encourage career progression and leadership opportunities not limited to direct support positions.
- Where available, provide access to other external supports such as a Community of Practice to ensure connection to the LLE community and ongoing professional development.¹³

LLE participation – via consultation, partnership and control

In settings such as advocacy, education, leadership, programs, policy, and research.

Involving people with LLE in decision making and problem solving is another valuable way to include LLE in the AOD sector.⁶ It recognises that people who access the services should play a central role in designing and delivering the system and its services.

There are many different models used to outline levels of LLE participation.

For the purpose of this document, we're using the **Ladder of Participation** (see P.22).⁶ Another useful model for describing engagement levels is the **Pyramid of Involvement** (see P.11).¹⁹

The Ladder of Participation includes three levels of LLE engagement: consultation, partnership, and control. Across these levels, people with LLE share their experiences and contribute to (and in some cases control) decision making.

Consultation is when people with LLE are invited to provide feedback; however, the service or organisation has the final say. This can include focus groups, suggestion boxes, surveys, interviews, and workshops.⁶

Partnership is more involved than consultation, everyone is an equal partner in decision making. This helps to ensure the voices of people with LLE matter as much as the voices of the other people in the room.⁶ Partnership examples include staff selection panels, steering committees and advisory groups.

Control is more involved again and incorporates LLE at all stages. People with LLE make all the decisions and have control of the resources.⁶ This can include LLE-led programs, projects or organisations.

Where capacity and resourcing allow, control is best practice for LLE participation. This type of involvement enables the highest level of LLE leadership and influence and helps to shift mindsets and work cultures to be more supportive and open to LLE involvement.⁶

The knowledge and experiences of people with LLE are diverse. LLE participation complements an established and sustainable LLE workforce within an organisation, providing broader and more diverse insights.

Engaging people with LLE and other intersecting identities, such as young people whose parents use/used substances, or someone who identifies as gender diverse and has experienced drug harms, is important for meeting the needs of a specific project or program.⁶



CONSIDERATIONS FOR INCORPORATING LLE PARTICIPATION INTO YOUR WORK

Collaborate early

- Involve LLE expertise from the beginning of the process. Where possible, ensure involvement before a funding proposal is submitted and deliverables confirmed with funders/management.
- Clearly define level of LLE engagement: is it consultation, partnership or control? Communicate this with participants.
- Integrate LLE expertise and leadership and collaborate on the aims, content and structure of projects.^{6,20}

Equity and inclusion

- Include the broader LLE community, as well as the LLE workforce, as both bring different perspectives.
- Ensure there's LLE representation in the facilitation of the sessions, so the LLE voice is fully connected and incorporated.
- When engaging with people with LLE, consider the purpose of the engagement and the insights you're looking for.
- Clearly communicate the purpose of the engagement when recruiting participants, so you can ensure they have relevant backgrounds. For example, are you seeking feedback from people who are currently using your service, have previously used your service, or the broader community?⁶

Support

- Some LLE workers may need specific resources and support while participating – ask them what you can do to facilitate these supports.
- Ensure additional training and support for roles requiring intensive or higher levels of participation, like facilitating focus groups, joining committees, or hiring processes. The Association of Participating Service Users (APSU) at SHARC provides training, support and resources for LLE participation.
- Utilise independent supervision and support to allow for safer and more open engagement, especially when concerns about the organisation are discussed.⁶

Payment and remuneration

- Allocate funding in the budget to compensate LLE participation, including the cost of any required supports and training. This demonstrates the value of their time and expertise.
- Tell people what the remuneration will be before they get involved.
- Consider other remuneration options, in addition to financial payment. This can include transport, meals and other out-of-pocket costs, certificates and references, assistance with accessing education and employment qualifications, attendance at your organisation's events or conferences, and use of office equipment and resources.
- It's best practice that participants are remunerated in cash, either cash in hand or via direct bank transfer. Be mindful when using vouchers, as it can imply people can't be trusted to choose how their money is spent.^{6,20}

Consideration of bias

- Facilitate a safe space for disclosure where possible by providing anonymity and/or allowing people to use pseudonyms, and ensuring the facilitation is supported by, or led, by LLE.
- Participants may fear being open about their LLE, expressing their concerns or giving negative feedback. They may also be worried about payment being withdrawn, or their ability to access services being affected.
- Invite multiple people with both LLE of their own drug use and family/carers with LLE to participate in consultations. LLE experiences are diverse and it's unrealistic to expect the experiences of one individual to be representative of an entire community.
 - For example, a person who injects/injected drugs will have different experiences to a person who was/is dependent on alcohol. Someone who experiences drug dependence while housed will have different experiences to someone who has experienced homelessness.⁶

How involving LLE improves programs and support

When LLE communities are empowered to work in, engage with and lead the AOD sector, there are benefits throughout the entire system.

It's well established that engaging with people who are, or have been, most directly affected by services, policies and programs is essential to understanding whether these different components are achieving their aims.^{21, 22}

People with LLE hold vital knowledge about what is needed, both for individual care and at broader levels. This experiential expertise can support more effective and efficient services, delivering benefits for clinicians, policy makers and funders, as well as for the people who use AOD services and their families and supporters.^{21, 22}

This includes improvements to how programs are developed and implemented, how the services are run in day-to-day operations and the knowledge that is used to inform these decisions.^{6, 12}

It's important to note that these benefits rely on LLE involvement in your organisation being established, embedded, supported, and sustainable.



Benefits of LLE involvement

PROGRAM DESIGN AND DELIVERY

- improves overall care and health outcomes
- increases accessibility and safety of services
- creates greater understanding of the personal impact of services
- informs improvements in innovation of services
- responds to the needs of affected communities.

SERVICE DELIVERY

- increases all staff satisfaction, safety and wellbeing
- supports better relationships between LLE workers and other AOD workers
- produces higher rates of service engagement and participation
- provides better outcomes for people who use the services, their families and supporters
- supports less coercive and restrictive practices, due to reduced power imbalances.

RESEARCH, EDUCATION AND INFORMATION

- increases workforce skills and confidence
- values experiences that are often stigmatised, leading to improved self-esteem and empowerment
- increases confidence to publicly share experiences in designated LLE roles
- informs areas of focus, understanding of research and translation of findings for research and policy
- sends a clear message that people who use drugs, their families and supporters are valued partners at all levels.

Incorporating LLE into programs and support

There is no one-size-fits-all solution for how to incorporate LLE into your organisation's practice.

But, there are dedicated LLE organisations, like SHARC or HRVic, that have resources, training and programs available to support you.

We encourage you to reach out to these organisations to help ensure thriving and sustainable LLE involvement in your workplace:

SHARC:

- Association of Participating Service Users (APSU)
- Peer Projects
- Straight from the Source
- Our Future
- Broadening the Source

Harm Reduction Victoria:

- Fuse Initiatives
- Stories of Stigma and Discrimination

Where can I learn more?

There is increasing interest in meaningfully engaging and employing people with LLE. And, the Department of Health Victoria along with many other organisations have developed resources and guides to support this process:

Department of Health Victoria:

- Lived experience
- Lived and Living Experience Leadership Strategy
- Workforce initiatives: lived and living experience workforces (LLEWs)

Victorian Lived and Living Experience Workforces (LLEW) Discipline Frameworks:

- Alcohol and Other Drug (AOD) Lived Experience Workforce
- Alcohol and Other Drug Family Lived and Living Experience Workforce
- Harm Reduction Lived and Living Experience Peer Workforce

Other resources:

- National Mental Health Commission – Lived Experience
- Insight – Understanding the AOD lived/living experience, peer workforce
- NADA – Lived experience insights: Improving access and equity in the alcohol and other drugs setting.



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