ALCOHOL AND OTHER DRUG (AOD) **FAMILY LIVED EXPERIENCE WORKFORCE** DISCIPLINE FRAMEWORK

This framework is part of a suite of five discipline frameworks for the lived and living experience workforces in Victoria:

- The Mental Health Consumer Lived Experience Workforce Discipline Framework (Victoria)
- The Mental Health Family Carer Lived Experience Workforce Discipline Framework (Victoria)
- The Harm Reduction Lived and Living Experience Peer Workforce Discipline Framework (Victoria)
- The Alcohol and Other Drug (AOD) Lived Experience Workforce Discipline Framework (Victoria)
- The Alcohol and Other Drug (AOD) Family Lived Experience Workforce Discipline Framework (Victoria)

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ACKNOWLEDGEMENT OF COUNTRY

The Alcohol and Other Drug Family Lived and Living Experience community acknowledges Victoria's Aboriginal and Torres Strait Islander communities as the First Peoples and Traditional Owners and custodians of the land and water on which we live, work and play. We acknowledge that sovereignty has never been ceded – it always was and always will be, Aboriginal land.

We acknowledge that colonial structures and policies remain in place today, and recognise the ongoing struggles of First Nations people in dismantling those structures. We know that cultural safety and capability is everyone's business, including the business of lived and living experience workforces and communities.

We express our deepest appreciation to the First Nations peoples for their generosity of time, knowledge sharing, expertise and support in the development of Victoria's lived and living experience communities. We are grateful for their resilience, wisdom and relentless pursuit of justice, as they inspire us to work together towards positive change. Our community has so much to learn from First Nations and we are committed to developing pathways and partnerships to support this.

The Alcohol and Other Drug Family lived and living experience community are grateful to First Nations people for teaching us the value of family and kinship and that these are so much more than who we are biologically related to.

As a community we embrace self-determination and reconciliation, working towards equality of outcomes and ensuring an equitable voice. We are committed to fostering meaningful partnerships, cultural safety and First Nations self-determination in our approach to lived and living experience work and the social change that underpins it.

A note on Aboriginal and Torres Strait Islander lived experience

This framework does not reflect Aboriginal and Torres Strait Islander lived experience. Aboriginal and Torres Strait Islander people have their own ways of understanding lived experience. Aspects of cultural identity, collective experience and lived experience of trauma, distress and service use inform how the experience is understood and expressed.[1] This lived and living experience is complex and based within a history of colonisation, intergenerational trauma, spirituality, cultural practices and protocols.[2]

CONTRIBUTORS

The development of this framework was made possible by the Lived and Living Experience Workforce Development Project 2022-2024, funded by the Mental Health and Wellbeing Division of the Victorian Department of Health. This project was commissioned in recognition of the value of lived and living experience workforces across sectors and supports a robust suite of workforce development initiatives to ensure these workforces are supported and continue to thrive.

This framework has been developed in collaboration with Family Drug and Gambling Help, a program of the Self Help Addiction Resource Centre (SHARC) and in consultation with Tandem Carers through the Mental Health Family/Carer Discipline Framework Content Development Group, the Carer Lived Experience Workforce Network and our Alcohol and other Drug Family Lived and Living Experience Workforce across Victoria.

GLOSSARY

Alcohol and Other Drug (AOD) sector: A collective term for all AOD services funded by the Victorian Department of Health and covered by the AOD Program Guidelines, including prevention, early intervention, harm reduction, treatment and ongoing support programs.[3] This includes AOD services available to all Victorians, targeted services such as Aboriginal and youth services and AOD services provided to people in the community as part of a court order.

Co-occurring needs: Describes a range of different support needs a person may experience at the same time. Generally, this refers to people who experience co-occurring mental illness (including people experiencing suicidal thoughts and behaviours) and substance use or addiction, with or without a formal diagnosis.[4]

Deep listening: AOD Family Lived and Living Experience workers practice deep listening, a skill based on respect learned from Aboriginal people. Known as 'dadirri', deep listening is an inner, quiet, still awareness.[5]

Designated and non-designated roles: The term 'designated' indicates a role in which lived and living experience is an essential requirement, in addition to relevant training, skills and knowledge.[6] 'Non-designated' indicates a role that does not require lived experience. Designated roles include all positions that require lived and living experience as key criteria, regardless of position type or setting.

Family: Those with a significant personal relationship with a service user including biological relatives and non-biological relatives, intimate partners, ex-partners, people in co-habitation, friends, those with kinship responsibilities and others who play a significant role in the service user's life.[7] Some family members may identify as a 'carer' in a service user's life, while others identify with the characteristic of their relationship (e.g. parent, child, partner, sibling).[8] 'Family' in this framework refers to family of origin and family of choice and the range of relationships, social connections and supports that many people have in their lives.

Family AOD lived and living experience: Family AOD lived experience refers to when a family member's loved one is currently in their own self-defined process of meaningful life change. Family AOD living experience refers to when a family member's loved one is currently experiencing the impact of substance use and/or addiction.

Family AOD Lived and Living Experience workers: A collective term for workers who draw on their life-changing experiences (current and past) to support and advocate for people impacted by substance use and/or addiction through a family perspective, minimising experiences of isolation, stigmatisation and marginalisation.

Living experience: Someone who identifies as having ongoing experience of substance use. It can apply to current substance use and/or related harms, to families whose experiences of supporting someone with substance use or addiction are ongoing and for those who choose to employ this term to reduce stigma associated with substance use and addiction.

Mental illness: Refers to a medical condition characterised by a significant disturbance of thought, mood, perception or memory, as defined in the *Mental Health and Wellbeing Bill 2022 (Vic)*.[9]

Peer: An individual with a connection to a specific community which acknowledges them as a peer.

Relational recovery: A process of relational recovery, working towards independence while maintaining meaningful connection, is also a core part of the family experience.[10] Relational recovery recognises that recovery processes are strongly embedded within family networks, composed of different individuals, relationships, roles and experiences. This process focusses on the healing of self and the mechanisms required to protect personal wellbeing long term in the relationship between the family member and the person experiencing substance use or addiction.

Service user: A service user is someone who uses, has used or is eligible to use AOD services. It includes people who are refused services or who refuse services. It also includes family and supporters of people who use services, regardless of whether they directly use these services. People affected by AOD policy and laws are also considered service users. Service users may also be known or referred to as consumers.

Substance use and addiction: Substance use refers to the use of alcohol or other drugs. In some cases, substance use can become harmful and negatively impact someone's life and/or that of their family. Some identify having a lack of agency in using substances and some identify as having agency, with their substance use a choice and right. Addiction is a medical term used to describe a condition where someone continues to engage in a behaviour despite experiencing negative consequences.[11] It can also be described as substance dependence.

A note on language

SHARC recognises the power of language, and that words can have different meanings to different people. Our experiences are personally defined and so too are our language preferences. Although striving for inclusivity, we understand not everyone will identify with the terminology used in this framework. To inform language use in this framework we have consulted with our rich and diverse lived and living experience community across sectors.

We have drawn from terminology largely aligned with the language outlined in *The Power of Words: Having alcohol and other drug conversations – A practical guide*[12], preferred terms adopted by the *Final Report from the Royal Commission into Victoria's Mental Health System*[13] and the language of our AOD Family Lived and Living Experience Workforce (LLEW).

The language of 'family'

Family is closely tied to themes of connectedness and kinship. For Aboriginal Victorians, family structures are pivotal to identity formation and spiritual and cultural belonging. The notion of family prescribes relationships and responsibilities people have to each other and the land. Ultimately, family and kinship are a cohesive force that binds Aboriginal people together.

The word 'family' in this framework refers to those with a significant personal relationship with a service user and includes biological and non-biological relatives, intimate partners, ex-partners, people in co-habitation, friends, those with kinship responsibilities and others who play a significant role in the service user's life.[14]

Some family members may identify as a 'carer'[15] in a service user's life, while others identify with the characteristic of their relationship (e.g. parent, child, partner, sibling).[16] 'Family' in this framework refers to family of origin and family of choice and the range of relationships, social connections and supports that many people have in their lives.

INTRODUCTION

Every profession needs a structure to support it, strengthen it and guide its development. In most cases, this structure is known as a discipline framework and is made up of all the elements required to understand the discipline.

The AOD Family Lived and Living Experience Workforce Discipline Framework (Victoria) (the Framework) articulates the AOD LLEW values, practice approaches and essential skills and knowledge for the workforce.

The Framework details the elements of the AOD Family LLEW discipline and is intended for current and emerging workforce, sectors, allies and stakeholders to:

- Increase knowledge of the Victorian AOD Family LLEW.
- Provide foundational understanding of AOD Family LLEW's professional practice.
- Provide guidance to people working with or seeking to employ AOD Family LLEWs.
- Support the ongoing development of the AOD Family LLEW in Victoria.[17]

The Framework has been developed in response to the Royal Commission into Victoria's Mental Health System (the Royal Commission).[18]

The Royal Commission's vision was for system transformation with lived and living experience at the centre. Realising this vision necessitates establishing strong foundational structures for the Victorian LLEWs where they are recognised, understood and valued, with the support structures afforded to any other profession. This Framework forms part of these foundations, delivering on recommendations in the Our Future report.[19] It has been developed in recognition of the families who have tirelessly advocated for the discipline and the Victorian State Government's investment in workforce development that acknowledges the invaluable contribution of all LLEWs.

The Victorian AOD Family Lived and Living Experience Workforce

What is AOD Family Lived and Living Experience?

While substance use and addiction are often viewed and treated as individual issues, or even as individual choices, they affect the entire social system of a person. Family members and significant others are particularly exposed to associated harms. Some conservative estimates suggest that for each person, at least two family members are negatively affected to the extent they need health care services in their own right.[20]

While there is no universal definition, as experiences are personally defined, lived and living experience as a family member is the experience, past or current, of being deeply impacted by someone's substance use or addiction and the challenges that often accompany it. This frequently includes supporting someone through, or witnessing, the harms born of and associated with substance use, a deep sense of shame and fear, losing and regaining hope, and navigating the grief of a life unimagined or lost either physically or in terms of identity. Regardless of these experiences, for a family member, the impact of substance use and/or addiction can radically change their lives.

A process of relational recovery, working towards independence while maintaining meaningful connection, is also a core part of the family experience.[21] This recognises that recovery processes are strongly embedded within family networks, composed of different individuals, relationships, roles and experiences. This process focusses on the healing of self and the mechanisms required to protect personal wellbeing long-term in the relationship between the family member and the person experiencing substance use and/or addiction.

There are many events in life that are valued, not only for the experiences themselves but also because of the insights gained about ourselves and the world around us. For the AOD Family LLEW, life altering experiences change the way in which systems of giving and receiving support are understood and elevate the power of inclusion and recognition – this is experiential expertise.[22]

GAINED THROUGH EXPERIENCE

It is not so much the particular lived experience that is important to Lived Experience roles, but the expertise and valued knowledge, skills and wisdom gained through this experience.[23]

> If parents had someone to talk to, someone who understood, who had been in that position or was in it now, then this could provide emotional relief and take off some of the pressure. This in turn may reduce the stress in their relationship with their child, improve communication and have a possible beneficial effect all round for the family.
>
> – AOD Family LLE worker, Victoria

Our history

The lived and living experience movement in Victoria has evolved over a number of years and now serves as a crucial part of Victoria's health and social service design and delivery. This history recognises the families, leaders and allies who paved the way, never letting go of the vision for a formalised AOD Family LLEW.

Families, carers, supporters and kin impacted by AOD use and related harms have been benefiting from peer-led support since the 1950s. This history begins with the establishment of Alcoholics Anonymous family groups and other non-profit mutual aid societies, where positive outcomes are drawn from fellowship and shared experiences.[24,25] Family members also played an integral role in the early recovery advocacy movements of the 1950s and have since established numerous peer-led formal advocacy organisations. In 1998, a group of Victorian family members, advocates and community members established a peer support group for families. From these efforts a peer-led service was built, initially on a voluntary basis, and today continues to provide connection, support, information and referral.[26]

In the late 1990s, AOD Family participation initiatives became prevalent through Victorian policy, and in 2000 the Association of Participating Service Users (APSU)[27] was established to drive strategic direction for participation activity and support the growing community of participants.[28]

In 2020, APSU released a practical manual for family participation for AOD services.[29] Family participation practice has since evolved significantly and remains highly valued as an aid to improve health outcomes and the quality of health care, as an important democratic right and as an accountability mechanism.

While people with lived and living experience of being a family member or carer have been employed in lived experience roles within Victorian public services since 1996, the work of the specialist AOD Family LLEW was historically performed on a voluntary basis. It was not until 2000 that the paid AOD Family LLEW started to emerge.

The expansion of workforce infrastructure as part of the Royal Commission's mental health reforms has supported the increase in the AOD Family LLEW across Victoria. An inaugural AOD Lived Experience family advisor role has been created in the Department of Health, supported by AOD Family lived and living perspectives in departmental advisory groups established as a voice to government. Additionally, Victoria's first AOD Family LLEW development officer was appointed in 2022 to support a dedicated effort in building the AOD Family LLEW.

The growth of the AOD Family LLEW is enabling invaluable family perspectives to be represented in service planning, delivery and evaluation, improving responsiveness to family needs and using lived and living experience to connect with and support families.[30]

VALUES

All professions are guided by certain core values that shape the practice and conduct of those within it. In the AOD Family LLEW, our values inform everything we do and are the compass by which we practice, make decisions and ensure our work is value based.

Core values	
 **Connection**	AOD Family Lived and Living Experience workers recognise connection as foundational to relationships, manifested through empathy and identification. Connection is the fundamental enabler in peer relationships, grounded in shared experience. Connection builds relationships and a sense of community where families can move from isolation, stigma and shame to belonging and acceptance.
 **Empathy**	AOD Family Lived and Living Experience workers practice empathy from a position of vulnerability and authenticity in relationship. Empathy is the ability to recognise oneself in another, without judgement. This identification can result in a deeply connective experience where families, perhaps for the first time, realise they are not alone.
 **Healing**	AOD Family Lived and Living Experience workers promote family healing, irrespective of the impacts being experienced. They work to empower families to move forward on their own self determined healing journey. AOD Family Lived and Living Experience workers recognise the need for family healing, which is often dependent on hope. Healing can begin with connection and knowing someone understands.
 **Empowerment**	AOD Family LLEW practice is strength based, underpinned by hope and recognition that each person can create a life that is meaningful for them. AOD Family Lived and Living Experience workers operate from a place of common humanity and vulnerability, recognising that goals, values, beliefs and choices are unique to each person. This includes the recognition a person is the expert in their own experiences and their journey should be self-directed.
 **Inclusion**	Lived experience work has its origins in advocacy for inclusion, social justice and human rights. AOD Family Lived and Living Experience workers elevate the right for families to be involved in decisions that impact them through direct and meaningful engagement in service and system design and delivery. AOD Family Lived and Living Experience workers are change agents who actively influence, advocate, improve service culture and quality and enhance the delivery of supports for families. Social change is born from amplifying the collective family voice to guide the transformation of systems, services, policies and laws.
 **Community**	The AOD Family LLEW is part of the rich Lived and Living Experience community. We share diverse histories and are unified by shared experience and common goals. This principle emphasises collaboration across the LLEW disciplines, sharing our experience, perspectives, work approaches, passions and expertise to help build the AOD Family LLEW.

SCOPE OF PRACTICE

The AOD Family LLEW is a collective term for the workforce where the primary qualification is that of lived and living experience and expertise as a family member impacted by substance use and addiction.

AOD Family LLE workers draw on life-changing experiences of witnessing, walking alongside and supporting someone through substance use and addiction, to support others facing similar experiences. They advocate for the needs of families, elevate the collective voice of the family experience and strive towards better outcomes for families through system transformation.

It is common for family members to have experiences of significant distress, loss, stigma, discrimination, loss of rights and the challenge of navigating complex systems. Regardless of the role, the work of the AOD Family LLEW is aimed at reducing stigma, feelings of isolation and helplessness.[31]

While roles and responsibilities within organisations vary, AOD Family LLE roles typically include:

- **Informational support and individual advocacy** – while primarily focused on empowering families with information, this support includes the provision of specific information about services, systems and rights, supporting system navigation services, or direct advocacy for individual needs.
- **Systemic advocacy** – advocacy at policy and service system levels delivered by AOD Family LLE workers is often connected to the collective voice of other families. Workers understand individual experience is connected to system change and are driven to improve services and outcomes.
- **Peer support** – is founded on the emotional connection of people with shared experiences. AOD Family LLE workers build relationships based on a collective understanding of shared experiences, self-determination, empowerment and hope.

Person to person roles

- Family peer support workers, family peer support group facilitators, family peer education facilitators.
- Work directly with families accessing and navigating services.

Service and system-based roles

- Family advisors, family consultants, family peer educators, family lived experience advisors and advocates, policy and project workers, researchers.
- May work directly with families accessing services as well as use Lived and Living Experience and skills to partner in building services, policies, systems and evidence.
- Includes being part of continuous quality improvement initiatives that make services more accessible, responsive and effective.

Governance, leadership and development roles

- Board positions, Committee and advisory, Executive, team leaders, managers, workforce development leads, Lived and Living experience supervisors.
- May work directly with families accessing services as well as leading other Lived and Living Experience workers.
- Includes working in systems, services and on projects that aid service improvement, change systems for the better and develop the AOD Family LLEW.

AOD Family LLEW roles are those in which lived and living experience and expertise is an essential requirement, in addition to role specific skills and knowledge.

AOD Family Lived and Living Experience workers often enter the workforce because of their desire to improve the system for others. They work to influence service providers and government to change practice and policy with the aim of better outcomes for families. Designated AOD Family Lived and Living Experience roles in Victoria currently include the roles below.

Peer workers

Peer work focuses on building relationships where self-determined healing is supported through identification, mutuality and connection. Peer workers play a key role in reducing stigma, minimising feelings of isolation and marginalisation, and increasing family inclusive practice. Peer workers walk alongside families, providing information and advocacy, and strengthen service quality through the inclusion of family perspectives.

Consultants

Consultants provide systemic advice and support at a program and organisational and policy level. The focus of consultancy work is service improvement through the family perspective, with particular attention to practices, policies and procedures that affect access and equity. Consultants are also employed to provide information, support and advice to people accessing services.

Managers and practice supervisors

Managers, coordinators, team leaders, practice leaders and supervisors deliver programs and services and may support and develop other Lived and Living Experience workers.

Advisors

Advisors in organisations, councils and government draw on the considerable body of collective AOD Family knowledge to inform systemic change and bring about change to laws, policy, procedures and bureaucracy that cause or perpetuate injustice or inequity.

Educators

Educators use their lived experience and learned expertise to deliver educational programs designed to support family members, increase understanding of the family experience or ensure educational content and delivery is informed by the family perspective.

Workforce development officers

Officers use their experiential expertise to facilitate the development of foundational documentation, training and other workforce supports for members of the AOD Family LLEW and organisations employing or working with them. The work involves ensuring the voice of AOD Family LLEW is captured within products and services to guide workforce growth.

Researchers

Researchers lead, guide and/or participate in all levels of research activity to promote the voice, value, function and outcomes of the AOD Family LLEW, adding to the growing evidence-base and supporting best practice and continued investment in the workforce. This leads to better support services and outcomes for AOD families.

SKILLS AND KNOWLEDGE

Lived and Living Experience work is principally about how experiences are understood and applied to benefit others. To deliver on this, the AOD Family LLEW requires both lived and living experience and the knowledge, perspectives, insights and understanding drawn from these experiences.

There is a unique set of skills and knowledge AOD Family Lived and Living Experience workers require to perform their roles. While many positions require specific skills and training, the following competencies have been identified by the Victorian AOD Family LLEW and their allies as important for the workforce to be effective across direct and indirect roles.

Professional practice

AOD Family Lived and Living Experience workers are committed to understand relevant legislation, policies, standards and systems and their practical application through AOD Family LLEW values. Working in teams and with a diversity of approaches, AOD Family Lived and Living Experience workers strive to:

- Maintain a whole-of-family, strengths based and trauma informed approach to practice, whereby all family members are considered when providing support.
- Understand how substance use, addiction and co-occurring needs impact the family and their experience of services.
- Understand the AOD system and service pathways, including the referral process and family services and what they provide.
- Deliver services according to legislation, organisational policies and relevant practice standards.
- Understand the various contexts surrounding substance use, including policies, legislation and other structural and cultural elements and how these impact on families and service users.
- Understand organisational change principles and engage in service development and quality improvement processes.
- Balance passion with adaptability and diplomacy, understanding that change takes time.
- Deliver inclusive practices by embracing diversity and delivering culturally safe responses.

Learning and professional development

AOD Family Lived and Living Experience workers identify areas where they can grow personally and professionally, taking opportunities to learn and develop. To thrive in their roles, AOD Family Lived and Living Experience workers:

- Recognise the value of and actively seek opportunities for, personal growth and professional development.
- Seek opportunities to enhance practice and provide mentorship for newer workforce members.
- Keep up-to-date with the latest research relevant to AOD Family LLEW practice and apply this learning to their practice.
- Network and maintain connection with other members of the AOD Family LLEW including discipline specific supervision to support effective practice.
- Regularly engage in reflective practice and co-reflection, utilising self-awareness to identify ways to continually improve practice.
- Protect and promote human rights, using personal experience and leveraging collective AOD family experience to advocate for positive change.
- Engage in ongoing learning to enhance culturally safe, ethical and inclusive practice.

> You really have to be able to talk to anyone and relate to anyone, and if you're the sort of person that finds it awkward or difficult to connect with others, it's not really the job for you.
>
> – AOD Family LLE worker, Victoria

PRIMARILY INFORMED

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.[32]

A WAY TO UNDERSTAND

Having an intersectional lens as a peer is a way to understand and explore the complex causes and effects of social inequalities in people's lives and how they impact individuals, family units and communities. It helps us remember that it is the barriers that are the problem, not the individual, their culture or their identity.[33]

> It is important to maintain a holistic approach where families are constantly in full view.
>
> – AOD Family LLE worker, Victoria

Connection and communication

AOD Family Lived and Living Experience workers use a range of skills to communicate appropriately and effectively with families, colleagues and other stakeholders. To be effective in building relationships and having influence, AOD Family Lived and Living Experience workers aim to:

- Use communication skills and styles appropriate to the situation and the people they are communicating with.
- Communicate effectively with diverse groups of people, balancing professionalism and respect with mutuality and empathy.
- Demonstrate communication skills that assist in developing connection in peer relationships e.g. deep listening and strengths-based approaches.
- Understand that being heard is about effective communication and building trusting relationships.
- Work collaboratively with colleagues to enhance the provision of services and supports through lived and living experience perspectives and actively participate in co-learning opportunities.

Self-determined wellbeing

AOD Family LLE workers understand self-care, self-advocacy and stress management are important for their wellbeing and resilience. As a priority, AOD Family Lived and Living Experience workers:

- Use wellbeing and resilience principles in their own lives and with the families they work with, utilising the practices that work best for them.
- Practically apply the principle of self-determination, supporting people to access the treatments, supports and services they choose.
- Know how to advocate for what they need to maintain their health and wellbeing.
- Use reflective practice to make the best use of their strengths and address areas where they experience challenges.

Role specific skills and knowledge

AOD Family peer work is a system of mutual support founded on respect, shared responsibility and mutual agreement of what is helpful.[34] This similarity and reciprocity[35, 36] is the essence of AOD Family peer support today and is complimented by the principles and tasks of Intentional Peer Support.

Peer support

The provision of peer support is based on a peer worker's ability to initiate and develop ongoing peer relationships. AOD Family LLEWs who are competent in peer support:

- Share their lived and living experience in an intentional way that supports identification, balances power and provides hope.
- Understand that peer support is about connection, having positive interactions without the need for an outcome.
- Seek to understand the unique family experience and how experiences vary for different family members, in order to meet them where they are at.[37]
- Have the ability and willingness to sit with discomfort and witness someone's truth without a need to rescue or fix.
- Negotiate the boundaries formal peer relationships require, while practicing mutuality.
- Acknowledge and work to minimise power imbalances, treating people as equals, while acknowledging the differing responsibilities in the relationship.
- Create a safe space for people to share their experience without judgement through connection, empathy and a willingness to practice vulnerability.

> **A family peer worker has many faces, they perform many roles, they are an expert in their own right, they are a shoulder to lean on, they are someone who can help steer the ship when the family member is unable to make sense of things and they can be change makers in people's lives—they are empathic humans who care and understand the struggles.**
>
> – AOD Family LLE worker, Victoria

- Support and empower families to make their own choices while encouraging them to move towards self-determined goals of relational recovery.
- Practice curiosity, active listening, reflection and creativity to bring to each unique relationship the kinds of supports that work for them.

Informational support and individual advocacy

Empowering families with information, this support includes the provision of specific information about services, systems and rights, supporting system navigation services and provision of direct advocacy for individual needs. This means AOD Family Lived and Living Experience workers can:

- Provide a sense of 'no wrong door' to families accessing services and facilitate warm referrals to other support services.
- Assist families to navigate the service system and access the support they need when they need it.
- Empower families to voice their needs and share their story when accessing services.

Partnership approaches

Partnership enables families to play an active and influential part in decisions that affect them and their communities. This work involves co-design, community engagement, networking, planning, evaluation, facilitation and communication skills. It requires AOD Family Lived and Living Experience workers to:

- Provide expertise to assist with services and system design and quality improvement initiatives.
- Understand participation as a human right – that people have a right to influence cultural, social, economic and political changes that affect them.
- Understand and actively address inequity and power imbalance faced through family engagement and participation activities.
- Understand and challenge the impact of stigma, discrimination, prejudice and human rights breaches.
- Actively network and consult with families who access the services in program, activity or service design to ensure their voices lead the design process.
- Understand participatory approaches, different levels of participation and opportunities to strengthen engagement approaches.
- Understand the principles of partnership and co-production to enable skilled and effective participation in these activities.

Systemic advocacy

Many AOD Family Lived and Living Experience workers, such as advisors, work strategically to effect positive change in service delivery and organisational culture. This requires that AOD Family Lived and Living Experience workers:

- Understand collective issues at a systemic and/or community level and work to affect positive change.
- Work to influence decision makers and use effective levers to achieve change.
- Provide strategic input from a family lived and living experience perspective in service, program or policy design.
- Elevate the voice of the AOD Family LLEW and advocate for AOD family partnerships and Lived and Living Experience leadership.

> Experiencing the profound impact of substance use and addiction on our lives empowers us with unique expertise derived from our personal journey. Through this shared experience, we come together to help shape the destinies of others, influence social change makers and indeed our world.
>
> – AOD Family LLE worker, Victoria

WHY FAMILY AOD LLE WORK?

The sense of disempowerment experienced by families impacted by substance use and addiction and the subsequent attempt to improve coping skills and social connections, has led to the development of the family AOD LLEW.[38]

The incorporation of AOD Family LLE workers in services and across systems is built on the idea of 'nothing about us without us' – that there is an imperative for the participation and involvement of AOD Family lived experience in service design, delivery and policy making.

First invoked by the South African disability rights movement in the 1990s, 'nothing about us without us' became the clarion call of activists organising to overcome systemic oppression and empower people with lived and living experience. Today it is recognised that AOD lived experience is an indispensable ingredient, essential to honouring human rights and representing genuine partnerships to deliver the best outcomes at individual, service, organisation and system levels.[39]

Engaging with people who are or have been directly affected by services, policies and programs is essential to understanding whether different components of the system are achieving their aims. This is because AOD Family LLE workers hold vital knowledge about what is needed from the system, both for individual care and family-inclusive practice, to broader levels. This experiential expertise can support more effective and efficient services, delivering benefits for clinicians, policy makers and funders, as well as for consumers and families.

Impact of AOD Family Lived and Living Experience work

Research into the impact of all forms of peer support is vast, and showcases a number of positive outcomes, particularly if the workforce is adequately supported. Evidence speaks to the multiple benefits of lived experience work for those providing the service, those receiving it and for the organisations themselves. Research shows Family LLE work results in reduced stress, loneliness, isolation and stigma due to:

- Emotional support and empathy not generally found in other roles.
- Helping families navigate the complexities of the health system.
- Bridging between families and clinical care teams.
- Connecting families to other services.[40]
- Unique expertise enhancing multidisciplinary teams.[41]
- Accessible and trustworthy practical support.[42]

People with AOD Family lived and living experience provide information and insights that can lead to better policies, more efficient funding allocation and more effective services.[43] Family involvement can:

- Improve the health of both consumers and their families.[44]
- Reduce reliance on health services and create more meaningful partnerships in systems of care.[45]
- Enhance system responsiveness to family and community needs.[46]
- Help normalise and spread the practice of family inclusion across the health system.[47]

A recent evaluation of family drug and gambling services demonstrated immense value in peer support for families including a reduction in social isolation, relief from shame and stigma, a feeling of connection with others who had similar experiences and a depth of understanding and authenticity provided by the AOD Family LLE workforce.[48]

For organisations, having the benefit of an AOD Family LLEW is not business as usual. A focus on the systems, processes and cultures that enable effective and meaningful LLE practice is necessary before introducing the workforce to the service. Capability training, resources and supports are required, and evidence shows that success relies on organisation-wide understanding, commitment and willingness to transform.[49]

SHARED UNDERSTANDINGS

It is not enough to employ people on the basis of their lived experience; shared understandings of how and why peer identity brings about change needs to underpin the role in all organisations.[50]

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16. Care relationships include a range of pre-existing relationships and people in them may not identify as a 'carer'. A care relationship is not only about what one person does for another person and can be reciprocal.
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