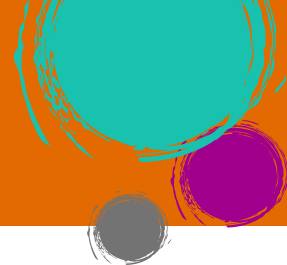


# A GUIDE FOR ENABLING LIVED EXPERIENCE INVOLVEMENT AND LEADERSHIP TO THRIVE AND HAVE IMPACT IN YOUR ORGANISATION



The lived experience community is calling for improved involvement opportunities and increased leadership pathways across the mental health and social services sector. Lived experience involvement in service design, delivery, decision-making, research, evaluation and system reform are key principles in both state (1) and Federal (2) mental health policies and are embedded throughout the United Nations Convention for the Rights of People with Disabilities (3).

In this guide we outline the enabling conditions required for the meaningful inclusion of people with lived experience at all levels of the mental health and social services sector. It builds on policy guidelines, best practice advice and LELAN's expertise gained through being immersed in the lived experience space from grass roots to strategic levels in South Australia and nationally. We hope that it supports the building of genuine partnerships between services and people with lived experience for the benefit of people who use services and our communities as a whole.

## Our expertise:

As the lead lived experience organisation in South Australia, LELAN's connection to our community, and the work that we do gives us unique insights based on the collective perspectives and solution ideas of people with lived experience.

Central to our work is the Activating Lived Experience Leadership (ALEL) project that is a partnership between LELAN and the University of South Australia's Mental Health and Suicide Prevention research group. ALEL provides a road map for lived experience leadership and systems change. The findings have informed several pieces of work including a consensus statement for action in South Australia and a model for lived experience leadership, due for release in August 2021. You can read more about the project, the preliminary results, and the literature review at [www.lelan.org.au/alel](http://www.lelan.org.au/alel).

Through our commitment to collaborative partnerships, our projects, practice, and our principles LELAN demonstrates the change dynamics required for the active and meaningful inclusion of people with lived experience at every level. This is the collective experience and expertise that LELAN brings to the mental health sector.



*The people who experience the gaps, fallout and additional trauma that can be created by mental health services in the NGO sector are able to identify them the best, with the most clarity, and also express what would've been better. We must be involved in the design process to not only share the power and control with us, but to also ensure that what we ask for is what is delivered. There is so much expertise in lived experience that is ignored every time a service is designed without any consultation, resulting in the ongoing gaps that perpetuate the cycles of the mental health system. When we are truly heard, involved and considered valid in our expertise we increase the humanity of the services being developed and the ability for those services to truly meet the needs of who it is being designed for. [Emma, member of the lived experience community]*



## Defining 'lived experience':

'Lived experience' can be difficult to define and is often contested. As use of the term has grown across a range of sectors there are sometimes questions about what type or how much experience is enough, therefore it has become increasingly important to be explicit in our meaning.



*When we talk about lived experience at LELAN we mean personal experience of mental distress, social issues or injustice 'that has caused life as we knew it to change so significantly, we have to reimagine and redefine ourselves, our place in the world and our future plans ... Importantly, it's about learning how to use those experiences in a way that's useful to other people' (4)*

Lived experience is also highly dependent on the context. In the homelessness sector lived experience means expertise shaped by personal experience of homelessness or housing instability; in a public mental health service, lived experience should be informed by personal experience of accessing public mental health services. Lived experience involvement means that people with the relevant life experiences are supported to share expertise that has been shaped and informed by those experiences and by the collective knowledge of the lived experience movement or that community. It is not just about having relevant personal experience, it's about centring lived experience expertise in what we do to influence and drive change.

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

## In support of lived experience:

Australian mental health policy has promoted lived experience involvement since 1992 (5). The meaningful inclusion of lived experience, as well as recognition and expansion of the peer workforce, is embedded throughout the South Australian Mental Health Services Plan 2020-2025 (6). It is one of the eight standards outlined in the National Safety and Quality Health Service (NSQHS) Standards (7), and is highlighted throughout all the principles in the 5th National Mental Health and Suicide Prevention Plan (8). In 2020 'lived experience knowledge and insight' has been recognised as a key enabler for change by the National Suicide Prevention Adviser Christine Morgan (9).

When the unique perspectives, knowledge, insights, and contributions of people with lived experience are embraced at all levels of an organisation and across the social services sector there are many benefits.

These include service users having improved experiences of care and increased access to appropriate care; a better workforce experience with less staff turnover and improved workforce attitudes and wellbeing; services and support that have proven better outcomes; increased efficiency; and reduced costs overall (10). Lived experience involvement helps to build trust within communities, maximising the reach, traction and leverage potential of activities and services, improving the credibility and legitimacy of the organisation or service within the client group, the social sector, government, and wider society (11).

Despite the growing evidence and the release of national and state guidelines, frameworks, and reports that highlight the value of lived experience involvement at all levels, it is not structurally embedded in many services or organisations (12). For many there is a genuine desire to improve lived experience involvement, yet there is not always the knowledge on how to do it well. Here we hope to provide direction by describing the conditions that are required for lived experience involvement and leadership to thrive and have impact.



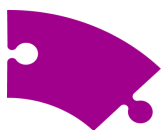
*I would hope every board would have a pillar in their strategic direction talking about inclusivity and equality that includes people with disability. As good governance, that should be there because every board needs a variety of lived experience to enable it to make the best decisions. [Kurt Fearnley AO, Company Director Magazine July 2021]*

## Enabling Lived Experience Involvement to Thrive and Have Impact:

Eight conditions for enabling lived experience involvement and leadership to thrive and have impact within organisations are highlighted in this guide. Each condition contributes in its own right to better inclusion of and opportunity for influence of people with lived experience, the greatest benefit for all parties however comes when all eight conditions are addressed.

This 'model' was formulated by LELAN's Executive Director Ellie Hodges in 2018. It emerged after extensive review of relevant literature and her own experience as a lived experience representative at state and national level in both personal and professional roles held at the time.





## Co-produced, or genuine partnerships at a minimum::

There are many ways an organisation can include people with lived experience. Examples include consultation and co-design initiatives, peer support roles, systemic advocacy positions and membership on advisory or reference groups and boards. The aip2 spectrum of participation demonstrates that different levels and types of participation achieve different goals (13), thus method must match purpose. In the case of lived experience involvement, true partnership, co-production or lived experienced-led action is recommended to achieve the maximum benefits from involving people with lived experience and the best outcomes for people using the services. To enable lived experience involvement to thrive, organisations and boards must go beyond inviting people with lived experience to share insight and perspectives only, to being willing to share power and provide real opportunity for them to influence decisions and outcomes. As service users, people with lived experience are likely to have been hurt as a result of power differentials, particularly people with lived experience of the mental health system or other statutory and institutional environments (including child protection, detention etc). In their publication on co-production in mental health contexts, Roper, Grey and Cadogen write that.



*'To avoid tokenism, harm or re-inscription of powerlessness and voicelessness, and to equalise power and influence, deliberate action usually needs to be taken, for example ensuring a project has a consumer majority or prioritises consumers' interests' (14).*



## Collective, inclusive, diverse and intersectional:

To authentically include lived experience perspectives, organisations must have a commitment to ensuring that diverse experiences of the issue being explored as well as diverse identity and cultural backgrounds are included. When mental health lived experience is overlayed with other lived experiences such as gender or sexual diversity, Aboriginal culture or alcohol or other drug use the overlapping layers of experience produce further challenges in addition to those that exist for either of the individual experiences. For example, there is substantial evidence showing LGBTIQ people have significantly poorer mental health and higher rates of suicide than other Australians and existing initiatives are not effective for this high-risk group (15). Aboriginal and Torres Strait Islander people experience high rates of mental distress, trauma and suicide with only half as many accessing mental health services compared with non-Indigenous Australians (16). Additionally the siloed nature of mental health and social sector services can cause people who use alcohol or other drugs or who experience homelessness specific challenges trying to access mental health support. By taking an intersectional approach in service planning, delivery and decision making, the complexities and insights of groups that experience multiple forms of systemic oppression, racism and/or injustice can be better considered. Making organisations and services more responsive to the communities' needs, effecting the services people can access, the quality of care provided, and reducing the stigma, discrimination and systemic failures that people experience.



## Value(s)-based and meaningful:

Centring lived experience is values based work, requiring everyone involved to bring a particular ethic and values focus to the relationships and interactions that develop. Trust, respect, recognition of the dignity of a person and a commitment to individual self-determination are vital components. For involvement to be meaningful people with lived experience need to be provided opportunities to set the priorities and agendas and be involved from the very beginning. This demonstrates that there is value and respect for the expertise of lived experience rather than it being an add-on or afterthought. The value of lived experience also refers to the economic value that lived experience involvement provides the system, the return on investment (ROI) of peer work has been calculated at \$3.27 for every dollar invested (17).



## Safe (enough) and supported:

People with lived experience have rich, diverse and complex histories in which experiences of trauma are common. In using the term safe-enough we accept that we cannot guarantee safety in this work, instead we acknowledge that 'doing harm by replicating oppression is always a potential risk. This is true despite our commitments to social justice and our collective ethics' (18). Vikki Reynolds promotes the idea of creating 'safe- enough' relationships and spaces and offers ideas about how we can work towards safe-r and safe-enough by intentionally structuring safety, 'Structuring Safety describes the practices of negotiating or co-constructing conditions, structures, and agreements that will make space for 'safe-enough' work' (19).



*There must also be a commitment to negotiating cultural safety and empowerment, creating 'an environment that is spiritually, socially and emotionally safe, as well as physically safe for people; where there is no assault, challenge or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience of learning together' (20).*

Being committed to authentic partnerships that negotiate safety reduces the chance of people experiencing re-traumatisation, enhancing the involvement experience and its outcomes for everyone.

Conditions that might be negotiated and that support safe (enough) relationships include making procedural changes and reasonable adjustments, being trauma informed and supporting people to become leaders by providing people with all of the information they need, promoting access to lived experience networks and opportunities for supervision, briefing and debriefing and educating staff and boards of the true value of lived experience to enhance their capacity for meaningful partnerships.



### **Backed by and with leadership:**

People with lived experience should be supported to develop leadership skills and abilities. Consideration should be given to potential training opportunities and pathways that enable lived experience leadership to progress.

The attitudes of senior managers, board members and organisational leadership is critical to partnering well with people with lived experience and successful involvement experiences. Leaders must genuinely believe in the value of lived experience and lead by example by making space for lived experience perspectives and contributions, supporting the development of lived experience leaders and sharing their platform and power.



### **Resourced:**

For meaningful and genuine partnerships to exist between services and the lived experience community, there needs to be adequate investment of time, resources and money to support both people with lived experience and service providers to create enabling environments that support the full inclusion of people with lived experience and their contributions. Some considerations include remunerating people appropriately, allowing for additional time to develop relationships and listen to each other, the provision of training and the development of resources, ensuring adequate briefing and debriefing exists and the developing of inclusive policies and procedures.



### **Integrity of process, developing capability and capacity:**

The recruitment and selection of people for lived experience roles should consider the skills, knowledge and experience that is required. For the recruitment process to have integrity it should be transparent, accountable, and fair. Selection based only on the lived experience status and not skills and knowledge, has the potential to be tokenistic or harmful. Organisations and services have a responsibility to develop the capability of people with lived experience to enable them to fulfill the duties of their roles. Equally, organisations and services must take steps to strengthen their own capacity for being responsive to the contributions of people with lived experience. Initiatives might include broad scale organisational training to promote and support lived experience involvement and leadership and having a clear position or framework on how people with lived experience are involved and supported.



## Embedded:

Mechanisms for lived experience involvement must be embedded in organisational processes, practices, structures and governance, including composition of the board. Embedding the commitment to partnering with people with lived experience allows for greater accountability and ensures that lived experience leadership can thrive beyond individuals within the organisation that champion it. It can then be supported by policy, procedures, planning, feedback and evaluation processes that permeate the culture of the organisation and makes it endure.

## Conclusion:

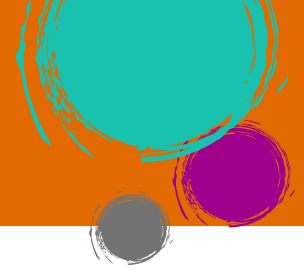
Involving people with lived experience and supporting their leadership can be helpful in their own journey and offers benefits for organisations and the broader sector. The full inclusion of people with lived experience at all levels, having mechanisms for people who use services to hold them to account and strategies for the empowerment of people who are impacted by them are all central principles of a human rights based approach (21). The United Nations Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health recommends that 'The meaningful participation and empowerment of all stakeholders should be promoted, in particular of groups in vulnerable situations' (22). Ultimately, mental health and social sector organisations having decision making processes that include people with lived experience is a human right and social justice issue. People deserve to have a seat at the table when decisions are being made that affect them. When self-determination is fully supported it means that people with lived experience are meaningfully included and provided with space and opportunity to lead.



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