A Roadmap for Strengthening Lived Experience Leadership for Transformative Systems Change in South Australia

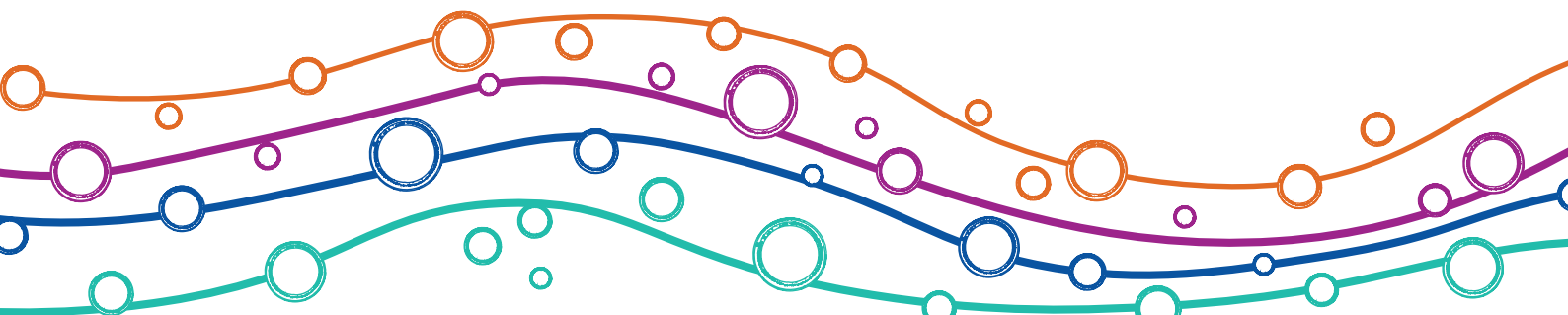
Activating Lived Experience Leadership (ALEL) Project

Acknowledgement of Country

We acknowledge the traditional custodians of country throughout South Australia. We value their cultures, identities and continued connection to country, waters, kin and communities. We pay our respect to Elders past, present and emerging.

Acknowledgement of Lived Experience

We also acknowledge the lives and work of people with lived and living experience, as well as our supporters and allies, who shoulder us up and who we shoulder up as we act to strengthen the voice, influence and leadership of lived experience in South Australia.



Acknowledgments

The SA Lived Experience Leadership and Advocacy Network and UniSA's Mental Health and Suicide Prevention Research and Education Group offer thanks and recognition to the Fay Fuller Foundation for the significant support and funding of the Activating Lived Experience Leadership (ALEL) Project.

Many people have been involved in and support this project as advisers, research participants, members of the lived experience community, sector leaders and allies. Thanks for sharing your wisdom and hard won experience with the project team and contributing to our collective vision and understanding. You helped us unearth and grapple with these ideas, and your words have directly shaped the language we use.

We acknowledge the commitment and guidance from members of the Project Advisory Group (PAG). Thank you for sharing your passion, knowledge and commitment in continuing to shape the key directions and substance of the project.

We also thank participants of the first and second System and Sector Leaders' Summits in working collectively to identify system barriers and opportunities, priorities and set future directions for lived experience leadership in SA.

All quotes used in this document by lived experience or sector leaders are from people who participated in the research activities of ALEL. They are used to bring voice to the Roadmap, and to share experience and insights.

Suggested citation:
Loughhead, M, Hodges, E, McIntyre, H, and Procter, NG 2021, *A Roadmap for strengthening lived experience leadership for transformative systems change in South Australia*, SA Lived Experience Leadership and Advocacy Network and University of South Australia, Adelaide.

ALEL Project team

Ellie Hodges, Project Lead
Mark Loughhead, Research Lead
Heather McIntyre, Research Assistant
Nicholas Procter, Research Governance

Project Advisory Group

Anne Barbara
Brooke Bickley
Geoff Harris
Jill Chapman
Julia McMillan
Lee Martinez
Leticia Albrecht
Lisa Huber
Richard
Sean
Tania Smith
Tayla Reynolds

LELAN
SA Lived Experience Leadership & Advocacy Network

University of South Australia

FAY FULLER FOUNDATION

Language and terms used in the document

Lived experience (LEx) leadership

This is an emerging term. We approach this work with an understanding that mental health lived experience leadership is where people stand up and speak up for the recognition and valuing of lived experience and advancing the movement. This includes informal and formal activity which promote the values and goals of lived experience as relating to empowerment, peer services, social justice and citizenship. Leaders speak up to influence community awareness, organisational culture, policy and politics; leaders create space, pathways and inclusion with others; leaders prompt and support change.

Throughout this project, we have used lived experience leadership to include both consumer and carer focused action, and consumer and carer leaders have worked together over the project. We acknowledge there are significant differences in perspective, and that nuanced understandings and practices are required which recognise consumer leadership and carer leadership separately. The principle that consumer voice should be the primary voice when referring to lived experience of distress, personal trauma, other mental health issues and use of services, and the leadership of the consumer movement, needs to be consistently acknowledged and respected.

We also recognise that lived experience leadership occurs across diverse communities and within different service areas. With a focus on diversity and intersectionality, there are times when we recognise that lived experience needs to be understood from different standpoints of experience and identity. This for instance includes LGBTIQ+ advocates working for suicide prevention, or other areas of inclusion, or leaders who are active in multiple service spaces at once. It is important to have a focus on mental health lived experience and designated roles as well as other areas where people are advocating for change from a social justice, lived experience perspective.

This work has validated our belief that LEx leadership is a key lever for transformative systems change and that the timing and conditions for truly embedding it and having its potential realised is now.

Lived experience

All aspects of the ALEL project are informed by the following definition of lived experience:
Experience, *'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' (Byrne & Wykes 2020, p. 243).*

My vulnerability is my strength,
and my strength is my vulnerability.
[LEx Leader]

Contents

1. Introduction and purpose: The Activating Lived Experience Leadership (ALEL) Project

In 2019 the SA Lived Experience Leadership Advocacy Network (LELAN) and UniSA's Mental Health and Suicide Prevention Research and Education Group (MHSPRE) were successful in gaining funding from the Fay Fuller Foundation to establish the Activating Lived Experience Leadership (ALEL) project. The ALEL project was designed as a participatory action research (PAR) and community development project, bringing people together to improve the way that lived experience leadership is defined, recognised and utilised at the systems level.

The research functions of the project conducted focus group and survey research with established and emerging LEx leaders, as well as interviews with South Australian system and sector leaders. This work was complemented by community development activities focused on connection, collaboration and mobilising the LEx community. These have included workshops on using literature for research and systems change, an ongoing community of practice on LEx leadership, two System and Sector Leaders' Summits, and accompanying interviews. The project team has also mapped LEx networks in the state to support ongoing communications and learning opportunities. Importantly this funding led to the establishment of LELAN as a LEx peak body in SA, contributing immensely to the opportunities for collective action and LEx-led initiatives. LELAN has been able to strengthen the development of LEx networks and its consultancy work in facilitating coproduction with organisations and policy makers.

The generation and analysis of research findings have been woven through the community development activities, creating awareness of the potential of LEx leadership in systems level change and fostering commitment to action.

Three documents have been developed to encapsulate the work of the project:

- The current *Roadmap for strengthening lived experience leadership for transformative systems change*
- A *Model of lived experience leadership* as a learning resource
- The *Strengthening lived experience leadership for transformative systems change: A South Australian Consensus Statement* of key actions for systems change

The purpose of this Roadmap is to detail the strategies and processes that organisations can undertake to better recognise, value and embed LEx leadership across the mental health and social sector eco systems in South Australia.

As a planning resource, the Roadmap describes the key rationales, research findings and observations that have been generated through the ALEL project. To focus the directions of this work, the Roadmap centres on the eight key actions that were endorsed via the project's second System and Sector Leaders' Summit. These best express sector and LEx leaders' collective views on the actions that would have the most impact in South Australia if undertaken in a coordinated and consistent way.

Key actions for leveraging LEx leadership in systems change efforts

- Increase the presence of LEx leaders in governance. Ensure more LEx designated director positions of boards, statutory councils and commissioning groups.
- Learning and cultural change programs of LEx leadership are arranged with executive leaders, staff and communities focussing on diversity of LEx leadership, supports, preferences and working through stigma and othering.
- Strengthen learning pathways and leadership skills development for people with LEx and enable and encourage opportunities for them to lead and provide advocacy. Enable easier access to professional development and formal qualifications.

- Fund leading LEx organisations to develop and deliver networking activities, including coordination of information, activities and events that support local LEx leadership, community initiatives and voice across diverse population groups. Focus on intersectionality.
- Enable resource flows for meaningful coproduction of all services and programs. This should include training of coproduction facilitators and chairpersons, and funding equal places at the table for LEx advisors and leaders.
- Promote LEx leadership and accountability measures through service agreements, KPIs and, where appropriate, regulatory frameworks and legislative processes.
- Ensure models of care include equal recognition of LEx workforces and peer support.
- Ensure a range of organisational and sector infrastructure for the effective recognition, valuing and embedding of the LEx workforce.

Working through the Roadmap

There are different sections of this document, with each explaining the territory of systems change, our research findings and leadership aspirations.

Systems change
The Roadmap covers significant territory and starts with a focus on systems change methodology and the value proposition of LEx leadership.

The current state
The current state of conditions in South Australia is then explored, identified mainly through research findings with sector leaders and LEx leaders. This also includes a summary of challenges and barriers experienced by participants.

Conceptualising LEx leadership
This identifies the main values, qualities and skills expressed by LEx leaders in taking initiative for change. An emerging definition is offered to assist clarity.

Important considerations
Following on, the map raises key considerations that shape how LEx leadership is perceived, organised and supported. These include a focus on expertise, values and justice, recovery and citizenship, intersectionality and allyship. The context of staff and leaders with LEx who are not 'out' or in designated roles is also considered.

Who needs to know, and who needs to lead?
This is a section of the map for identifying your role in contributing to change and how shifts in structures, relationships and power can be enacted locally and from all vantage points.

Shifting current ways, prioritising action
The map then progresses to summarise research findings about preferred change in South Australia, outlining possible actions that participants recommended and which were presented to sector leaders during the second System and Sector Leaders' Summit meeting. Eight priority actions are presented that were endorsed for our state and from the Consensus Statement.

Vision for change
The end of the map describes a collective vision of change that was articulated during the second System and Sector Leaders' Summit. Compassionate care, accountability, empowered decision making, an end to discrimination, and services which uphold dignity is the transformation that is needed.

Project background

The approach of the project was developed by LELAN and UniSA, after observing and reflecting on enduring patterns and gaps in the ways LEx leadership has been developed and resourced in South Australia. This included learning from consultative work completed by one author of this report for the former SA Mental Health Commission on the need for a peak body in SA (South Australian Mental Health Commission 2018).

These patterns are common across Australia and reflect that LEx leadership is an emerging concept and practice, but also one which is either facilitated or hindered by the institutional context and power of mental health organisations (Loughhead et al. 2020). These include:

1. The predominance of a participation or involvement context, where people with LEx are invited to be involved in conversations/decisions by organisational or policy leaders. This means that established organisations mostly set the agenda for groups, or as empowering bodies, are able to both create and dissolve advisory structures and councils, limiting the positional power and potential influence of LEx leaders. A limited focus on involvement and even partnership means that LEx leaders mostly operate as advisors, rather than as people who can lead services or organisations and decision-making.
2. The gradual growth of the LEx workforce mostly expressed in the uptake and employment of peer support workers in Local Health Networks (LHNs) and non-government organisations (NGOs). This is a very positive development but has become the primary theme of LEx development in the state. An equal focus on effective representation, systems advocacy and building LEx capability and pathways/networks of support is often missing from policy and planning. This limits the practice and resourcing of effective coproduction at a governance level, as well as the inclusion of diverse groups and opportunity for LEx-led action.
3. The enduring lack of a focused LEx mental health consumer peak body in South Australia (South Australian Mental Health Commission 2018), which can provide sector leadership, motivate and mobilise a collective broad-based LEx membership, influence policy, prompt action, and carry a strategic vision for longer term change. Relative independence from policy makers and service settings is important in enabling a peak body to be an effective voice and bring accountability into the system.
4. A building momentum in the LEx movement for a paradigm shift (O'Hagan 2009; Scholz, Bocking & Happell 2017; Stewart et al. 2019), where LEx leadership is recognised to have positive influence on political, policy, service and community levels. LEx leadership includes lobbying, decision making, commissioning, organisational leadership and board management functions.

Project aim

Aim: To undertake participatory action research (PAR) and systems change focus to enable LEx leadership to be recognised, valued and embedded across the mental health and social sector eco system.

Research questions:

1. What are the reasons why LEx leadership and advocacy is not well recognised, acknowledged or enacted by the health system? What strategies and practices are needed to change this?
2. What are effective strategies for embedding LEx leadership focused education, thinking and resources within communities and the South Australian health system?
3. What are understandings of the impact of LEx advocacy and representation on individual recovery from mental health issues including active participation in broader areas of life?

4. What do people with LEx say is needed in the design of training resources and networks to guide and support LEx advocacy, representation and leadership?

> ***I think that having a lived experience and being able to utilise it in this way is one of the greatest things because you're able to turn what was such a relentlessly bad experience into a positive. You're able to salvage beauty from the ashes of your experience; you've come out of the fire and you're all refined, and all the other metaphors you want to use. But it's exciting to be able to utilise. I think it's been huge in my personal recovery as well. [LEx Leader]***

Project methods: Participatory action research including formal research and community development

PAR is a well-known qualitative approach to generating knowledge to respond to social issues. It encourages wider participation of the people living with the issues under inquiry and shared planning, action, and reflection. The development of knowledge and action is an iterative process, where meaningful data collection and analysis is shared and refined over time. The project was framed as LEx-led insider research, which expanded to include the perspectives of carers, health practitioners and policy leaders. This required transparency in our analytical processes and acknowledgement of our interests in seeking improved recognition of the LEx movement and its value to organisations and systems when embraced.

The project included formal research and consultation processes. The first formal research step was to develop the study design and focus group questions with the Project Advisory Group (PAG). Seven online focus groups were then arranged with 31 LEx leaders participating. A diverse sample of participants were recruited to reflect different roles, such as community speakers, peer support workers, awareness raisers, advocates and project workers. Diversity was represented from members of LGBTIQ+ communities, CALD and Aboriginal groups, rural communities and people living with disability. Leaders working in suicide prevention areas were also included. Participants were asked questions about leadership, challenges, impacts on recovery, and changes needed for LEx leadership to thrive and have impact. An anonymous online forum was created where emerging themes from focus group discussion were posted and participants could add reflections. A further round of four focus groups were held focussed on reflections and questions about learning requirements and network development. Summative mind maps were created and shared as a way of organising themes and key meanings of the research. You can read about this work in the Summary Report on focus group research with lived experience leaders (Loughhead et al. 2021a).

An additional research strategy was interviewing 14 sector leaders with a similar range of questions. Summative mind maps were generated and compared with focus group findings. An online qualitative survey was a third strategy for seeking input, allowing participants from other states to participate. The responses from 48 people were included in our research, with this data both extending and confirming existing themes. Summary reports about the interview and survey studies are available (Loughhead et al. 2021b; Loughhead et al. 2021c).

Sharing the developing knowledge of the research with a wider audience occurred through several consultations and working with the PAG to refine, reflect and make sense of research themes. Consultation included the distribution of mind maps and observations to participants and the LELAN membership, and further sector leader interviews. Two System and Sector Leaders' Summits were also held in October 2019 and February 2021 (see Hodges et al. 2019; Hodges et al. 2021a) as a means of participatory action to test ideas and encourage a shared understanding, vision and commitment to change. Over 40 executive leaders across government and non-government agencies and sectors, including peak bodies, attended at least one of the Summit meetings.

2. A systems change approach for an enduring problem

The experience of the mental health system is enough for me to stay strong. It is so broken and so horrible to go through that it motivates me to be a leader for change. When it feels unattainable, I mentally take myself back to one of the health system service units we were in and it motivates me to keep going. [LEx Leader]

The ALEL project intentionally centred on a systems change focus to understand and act on an enduring problem that is mostly felt by people who do not have a positive experience or outcome from mental health service use, and the mental health LEx movement. Extensive service challenges in mental health systems continue to negatively impact consumers, carers and families across Australia (Productivity Commission 2020) and despite vocal support of LEx we do not see structures that support it being embedded across SA.

The problem is

a. that effective mental health services and programs need the input, perspective and contribution of people with LEx, so that services are planned, delivered, and managed to be truly helpful and empowering; and
b. that organisational and system responses for enabling the presence and impact of LEx voices are inadequate, remain underdeveloped, poorly funded and subject to the disruptions and shifting demands of the health system. Responses include mechanisms for coproduction and shared governance, pathways for leadership and skill development, systems advocacy, peak body presence and further development of the LEx workforce.

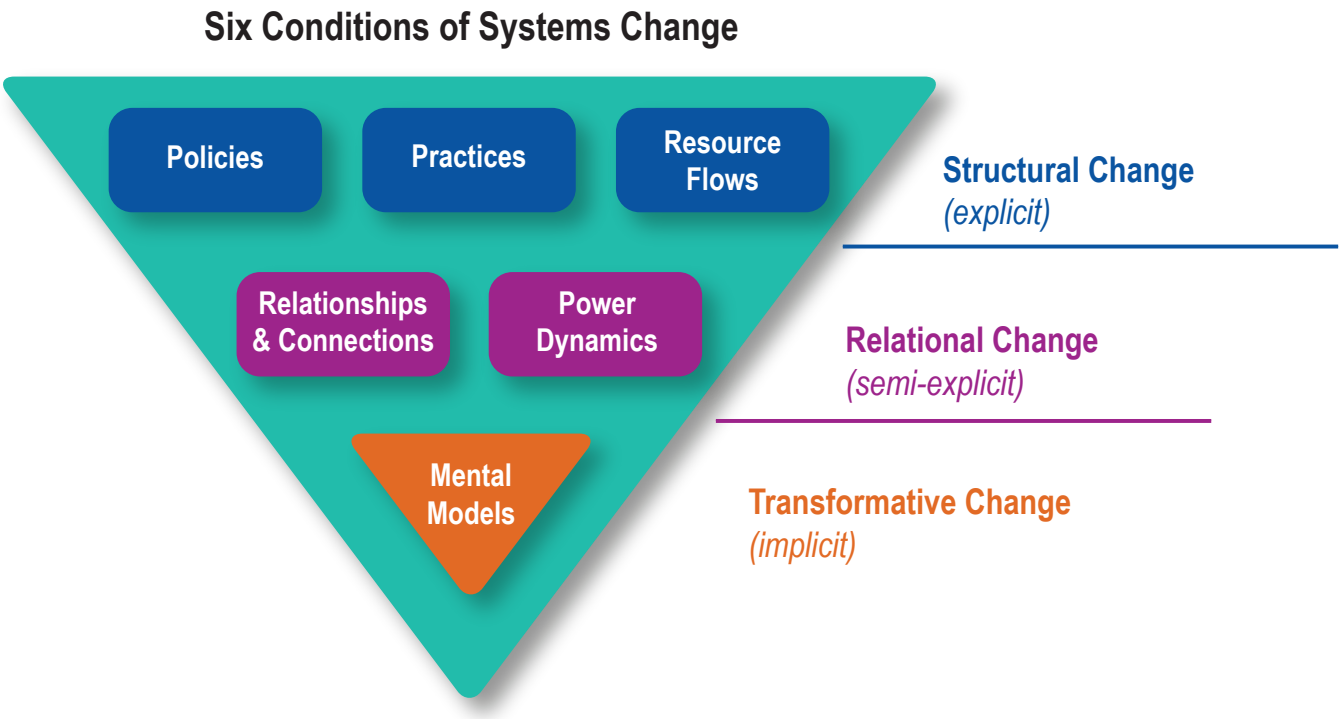
The problem is central to the value proposition of LEx leadership described on page 18.

A well-known systems change model underpins this work. The model by Kania, Kramer and Senge (2018) proposes that systems change needs to target multiple layers and conditions which make up the system. This includes aspects which are visible such as policies, practices and resource flows, as well as conditions which are less easy to define and capture i.e. relationships, networks and power dynamics between groups. The authors argue that all service systems have a pattern of dynamics and resource flows (decision making and influence, funding, distribution of workers and opportunities, etc.) that maintain their current operation and performance. For significant and lasting change to occur, actors need to see beyond their usual perspectives and positioning, to see and act on the various conditions which hold the system in place and prevent progressive change (see figure 1):

'Complex problems such as mass incarceration, educational disparities, and environmental degradation remain intractable due to myriad constraints that surround any specific program a foundation might fund. Constraints include government policies, societal norms and goals, market forces, incentives, power imbalances, knowledge gaps, embedded social narratives, and many more. These surrounding conditions are the "water" that many foundation leaders are exploring more deeply.

'One must then go further to explore the relationships among these actors, the distribution of power, the institutional norms and constraints within which they operate, and the attitudes and assumptions that influence decisions. These are the conditions that significantly impede or enable social change' (Kania, Kramer & Senge 2018, p.2).

Figure 1. The six conditions of systems change (developed from Kania, Kramer & Senge 2018, p.4).



Kania, Kramer and Senge (2018) argue that transformational change requires attention be paid to the mental models and dominant narratives of the system and its actors. These mutually reinforce beliefs about social problems, the changes required and who is best placed to carry these out. The approach highlights that mental models, assumptions and narratives are the most challenging to shift, as these beliefs are embedded in our workplace and community cultures, and influence decision making. In contrast, people using systems and services are often very aware of assumptions and beliefs that get in the way of quality care e.g., stigma about mental illness, medical model dominance and levels of functioning for eligibility.

Understanding the complexity of the mental health ecosystem is a challenging process and includes:

- Public mental health services, programs and networks as organised within LHNs and guided by the SA Department of Health and Wellbeing, which includes the Office of the Chief Psychiatrist (OCP).
- NGO mental health organisations funded specifically by state and federal governments.
- Community initiatives and networks which are voluntary activities and occur in regional, rural and remote communities as well as metropolitan areas. These include networks in Aboriginal health, LGBTIQ+ communities, CALD and refugee communities.
- Community sector NGOs in health, youth, aged care, housing, drug and alcohol, disability, low income and family support which contribute to the mental health and wellbeing of South Australians. This includes sector peak bodies.
- Primary care businesses and organisations that provide mental health services and are funded through Medicare and NDIS.
- Regulatory and standards bodies and legislation as well as and policy units and commissions.
- Universities and research groups.

I've had some really interesting conversations from people asking how much do we try and enter and disrupt and change clinical cultures, and how much should we establish our own services according to our values and professional needs. And I think both is really important. [LEx Leader]

A focus on multiple conditions and collaborative impact

The *Water for systems change* (Kania, Kramer & Senge 2018) invites consideration of all six conditions which impact on how LEx leadership is recognised, valued and embedded across the mental health and social sector ecosystem. It requires collective and collaborative action, with understanding that a single program is unable to generate the shifts that many LEx and sector leaders and allies would like to see. Part of setting a collective agenda is appreciating that change occurs on individual, organisational and systems levels, where each person can contribute.

'There's no systems change without organizational change and no organizational change without individual change' (Kania, Kramer & Senge 2018, p.16).

Systems change authors have examined key strategies and processes for collaborative impact. These are summarised by Kania and Kramer (2011):

Setting a common agenda – ensuring participants across the system have a shared understanding of the issues, and vision for change. This enables participants to generate agreed actions and act together. A big focus here is involvement and shared planning across community, organisations and funders.

Shared measurement systems – participants should work to identify what successful change will look like and how it will be measured. This requires shared indicators, which are taken on board across organisations and are meaningful at community levels. Organisations learn from each other's progress.

Mutually reinforcing activities – this recognises that different stakeholders act in a coordinated way, each contributing to the broader plan, in ways aligned with the stakeholder's strengths and agreed function.

Continuous communication – collaboration requires regular meetings and transparent communication to generate trust and commitment and help groups to develop a common language for describing the issue, planning, and taking action.

Backbone support organisations – specific organisations and skill sets are needed to provide support, infrastructure and governance for change projects, ensuring time, skills and resources can guide development, communication and working together.

There is a sector responsibility…We're a decade into this and sometimes it feels like we're not making any progress at all so there needs to be a sector wide...strategy and commitment to making it work. Not sure what that would look like but certainly some advocacy from that highest level about making sure that organisations have a strategy themselves about how to increase not just their lived experience workforce but people with lived experience in their leadership teams as well…There are obviously, some things in there that are challenging to, kind of, implement that type of approach but it's, and as I say, there needs to be that commitment from the very, very top of the organisation all the way down to make those cultural changes… we don't get it right enough for my liking. There's still a lot of work to do across the board for mental health services about the way that we deliver services and having, you know, lived experience people from service delivery through to leadership is one of the ways to really push through those, kind of, systemic changes that we need to do. [Sector Leader]

How the ALEL project worked with systems change processes

The project work of the team, PAG, research participants and sector leaders generated significant commitment and energy towards change.

The research process was used to build an analysis of common perspectives regarding LEx leadership, including key challenges and barriers, the values, qualities and skills of effective leaders, preferred pathways and networks of learning and supports, and appropriate targets for organisational and systems change and what is required for it to thrive and have impact. The data set of research and community development activity learnings gives the project tremendous insight into current conditions that LEx leaders, and sector leaders face as well as identified targets and energy for change.

At the same time, LELAN has continued to build networks of LEx across multiple projects and activities in the sector and working with agencies and policy makers in pivotal codesign processes and lived experience-led projects. This work has exposed many people across the system to systems change models and thinking, and the value of LEx. LELAN has secured federal funding for further LEx leadership skills training, creation of learning networks and initiatives to match people with LEx to governance sub-committee and board roles.

Two System and Sector Leaders' Summit events were convened to bring people together for agenda setting and a commitment to action. The first Summit in October 2019 established an agreement that LEx leadership requires much better recognition and support in South Australia and explored key conditions that limit progress in SA. A Community of Practice on LEx leadership and systems change resulted, to share learnings and create awareness of actions that could be taken in each person's own context. It highlighted the need for a collective framework of LEx leadership and the LEx workforce in SA, which has gained traction as a sector project since this time by and with other key stakeholders.

The second System and Sector Leaders' Summit February 2021 focused on creating a shared vision for change, as well as prioritising systems change actions identified through the projects' research. This Summit resulted in a *Consensus Statement* for embedding LEx Leadership in South Australia and a commitment of organisations to engage with priority actions included in the statement. This Roadmap is an attempt to detail the actions, outcomes, and forms of shared measurement that organisations can use to contribute to their own progress and this broader shared vision over time.

Drawing on research findings and community development activities, *The Model of Lived Experience Leadership* has been developed which organisations can use for strengthening leadership pathways and shared definitions and understandings. This model can be a basis for training, skills development and reflection for existing and emerging LEx leaders.

The ALEL project formally ended June 30, 2021. We are acutely aware that change in South Australia will require a backbone organisation or partnership to continue to drive this work and support organisations seeking to fulfil the *Consensus Statement.* Continued meetings and support are required to assist the sector in coordinating activity, communicating shared commitments, measuring progress and learning from each other.

3. The current state of LEx Leadership in South Australia

This section relates findings and observations on the current trends of mental health LEx leadership. As the journey towards systems change starts, there needs to be a realistic assessment of trends and patterns within services and across the sector. What are some of the aspects where SA is doing well? What are key challenges and barriers as seen from different perspectives? What are the strategies and actions that need to be clarified and discussed?

LEx leader perspectives

Assessment of the current state and trends of LEx leadership were evident across the focus group research of ALEL. It was recognised that the lived experience workforce, in terms of the numbers of peer support positions is growing and that organisations are investing in building this workforce. For participants in peer work positions, many reported significant gaps in training, supervision and support. Some participants reported struggles in having lived experience perspectives valued by managers, and having their roles clearly understood. Participants who were not currently employed as peer workers noted the difficulty in accessing qualifications and learning pathways, and that limits existed for entry into formal Certificate IV Peer Work qualifications. Many participants noted that peer support work is not well understood across the community, and they themselves came upon peer work opportunities by accident. The language of lived experience itself is not commonly used and understood, especially in diverse, CALD communities. A significant focus on community level learning needs to occur, as well as sector level learning.

In terms of systems advocacy, and participation in decision making, participants felt that learning pathways remain underdeveloped, with few opportunities for learning about effective advocacy, and limited supports when active in this space. Participants reported ongoing challenges in working within services and programs where clinical paradigms were dominant in service design. Part of this experience was making decisions about the best ways to push for change, recognition and learning how to do this well. Many people reported the constant work of having to 'educate outwards' about lived experience and recovery values, in settings of limited support.

> ***I would just say that, a few years into my role as I learned, it took me a long time to learn what I was doing in the role because I had no or very little, very limited guidance and mentorship or supervision, almost non-existent. It was a year – I was a full year into my role before I was even offered any training about peer work, which is pretty poor. And I was pretty much figuring it out on my own and doing my own self-education but, following that, I continued to self-educate as much as I could and seek out as many training opportunities as I could. And as I actually figured out what the role was and gained a bit of mastery over actual peer work, I started to get a lot more concerned about the state of our working conditions, the state of our profession in comparison to other professions in mental health, how differently managed and supported they are and the direct consequence I could see for myself and my colleagues in their career progression, and all sorts of things like that. How integrated or not we are in clinical cultures, all of those concerns that we know about I started to see and really think about. And just a couple of years ago, I had some opportunities where I could be a lot more outspoken and actually speak up to management when it showed that they were really ignorant about my role in my service, my capacities and their expectations on what I would and wouldn't do. [LEx Leader]***

Sector Leader perspectives

Trends where LEx leadership is evident and emerging

Through interviews with sector leaders, we learnt that LEx leadership was most prevalent in the areas of consumer and carer involvement in organisational planning and in the growing LEx workforce. Presence at consultations and the contribution of peer support workers to organisational life was identified by most sector leaders, with people citing the effectiveness of various LEx registers and mailing lists for enabling information flow, and the successful evolution of peer support work roles. They also named LEx leaders presence in governance and policy development as a further area of achievement, but this finding was less consistent across all organisational contexts. Many participants noted a lack of LEx presence on boards of management. The high profile and involvement of LEx leaders in the suicide prevention area was a key theme where South Australia is developing well. This is in terms of community speakers, community developers and policy advisors.

Absences and uncertainties

Sector leaders noted three areas where absences contribute to the underdevelopment of LEx potential. These included a lack of dedicated budgets for resourcing involvement activities and pathways, questions on the capacity of organisations to enable genuine coproduction, and a lack of KPIs at executive and board level to drive organisational development.

This research also noted some key issues requiring discussion and clarity:

- What is the best ratio of LEx and non-LEx positions within an organisation?
- How is the LEx of existing leaders in non-designated roles recognised and appropriately voiced?
- How do people with LEx in both designated and non-designated positions (e.g. board members or team members) work together?

> ***My perception at the moment is that the drive for lived experience is coming from a few organisations who have embraced it, and other organisations in the system who have just gone, 'Oh, this sounds like we should be doing it, so we had better just say we do it.' Unless you have, I think, people in that bigger larger systems perspective looking at it and pushing it and being outspoken about it. [Sector Leader]***

> ***I think there's at least an intellectual willingness for this now. There might not yet be an emotional willingness but there's an intellectual willingness because I think most people now get the value of lived experience, at least from a political perspective. So, it does give you a bit of power hopefully, to push some of the stuff you're finding here. [Sector Leader]***

Specific challenges and barriers

This assessment includes extensive qualitative data on an array of challenges and barriers experienced by people within the LEx movement as well as sector leaders. In terms of a systems perspective, they have been summarised into four categories.

These include:

1. LEx leader experiences,
2. structural features of the systems people operate in,
3. relationships and power dynamics, and
4. assumptions of current collective mental models and mental health narratives.

What LEx leaders told us:

Issues internal to the LEx movement
Challenges involved in 'coming out', or 'being out' in terms of experiencing and confronting stigma, or how stigma limits the number of people being out as LEx.

Appropriate boundaries and skills for using personal/family stories safely and impacts for small communities. Underdeveloped understandings of LEx leadership, which remains an emerging concept. How leaders need to 'manage up', be the bearers of change, and the shift to being seen or viewing themselves as 'leaders'. Conflict experienced internally or externally due to role tensions, disagreements, or lateral violence within the LEx community.

Structural barriers
Features of current funding and resource flows where stigma, deficits and paternalism shape interactions and opportunities available to emerging LEx leaders.

Challenges in relationships and power sharing
Isolation within roles, linked with a lack of supports and learning pathways to mentoring and peer-based supervision. LEx information and leadership networks are underdeveloped or access isn't fully recognised by employers.

Exposure to various stresses, demands and inner conflicts which reflect tension between recovery, LEx and medical perspectives on mental health, or experiences of othering and power differentials. Frustration and burnout.

Issues on identity, sexuality, gender and culture not being recognised or supported by involvement processes, where framing of LEx roles by organisations do not recognise intersectionality. Experiences of volunteering. Includes pressure of being the expert, go-to person. Problems with representative roles, setting boundaries and self-care.

Challenging assumptions about people with LEx
LEx views, knowledge and roles not understood or valued within the broader mental heath community, including some mental health teams and organisations.

What sector leaders told us

Issues internal to the LEx movement
Uncertainty surrounding people with LEx in non-designated roles (clinicians, team leaders, managers).

Structural barriers
Lack of dedicated resources and infrastructure, including various barriers within human resource/industrial rules for funding and organising coproduction processes which achieve involvement of diverse voices.

Establish culture of risk and control shaping interactions and relationships, including workers resistant to LEx involvement and coproduction.

Challenges in relationships and power sharing
A lack of supports and pathways, particularly for enabling diverse involvement within service planning across metro and non-metro areas. LEx leaders often experience being the only 'go to' person, maintaining isolation. Lack of coproduction facilitation capacity.

Stigma limits more people coming out, stereotypes on the LEx leaders and the workforce, and shapes decision making within organisations.

Challenging assumptions about people with LEx
LEx not understood, valued or possible. Including token efforts, poor recognition by leaders, and barriers due to the burn and churn of the system and slow change.

Observations and conclusions

This section has summarised perceptions on the key challenges and barriers impacting the achievements of LEx leadership in South Australia, as well as outlining views on successful development opportunities.

The ALEL project observations on the current state are:

LEx leadership has complexity: leaders are 'pioneers' in seeking change within organisations and systems, including challenging existing cultural narratives, they therefore often experience multiple relationships, contexts and dynamics to navigate and work through. Complexity occurs in the processing and negotiation of relationships and perceptions about LEx and mental health. It connects an individual's personal, professional and socio-political worlds in unique ways, which requires support, recognition, and space for learning and self-reflection.

Organisational and community understandings of LEx involvement and leadership are immature at a systems level. There are examples of good work across places, services and networks. There is considerable overlap between the views of LEx leaders and sector leaders in identifying challenges, but also key differences. Both groups can have specific and limited views, seeing their experience from the contexts of peer support work, suicide prevention and advocacy/coproduction spaces. However, there is not a developed understanding of the potential of LEx leadership for transforming the way policy, systems and organisations and decision-making are produced and delivered. There is limited knowledge on how to apply, support, develop or embed LEx

leadership. These trends are found across literature in peer support implementation (Walker & Bryant 2013), and supporting leaders involved in advocacy and representation (Dent 2011; Scholz et al. 2017; Bennetts, Cross & Bloomer 2011).

Promising work is occurring in the suicide prevention area, where a community development approach is taking place. Opportunities for working together and planning community events and conversations are empowering for LEx leaders and community members, where they can identify needs and preferences and lead local initiatives.

Pathways for people with LEx, in both peer work roles and advocacy/representative roles, are underdone and often defined by services and systems rather than by the LEx community aligned with the movement's values and approaches. Summit level discussions reflected that LEx leadership is often lost in the burn and churn of large services and shifts in system demands. There needs to be pathways and organisations where LEx leaders have increased presence and power in shaping agendas and driving change (see Hodges et al. 2019).

I think that lived experience leadership and indeed any service development leadership or service reform leadership needs space to practice in real world settings, and we don't have that. Or at least we don't have it articulated. It's really informal. [Sector Leader]

I spent a lot of years waiting around for someone else to come and fix all this stuff for me and then the day came eventually when myself and my other colleague, who I partner with a lot, we're co-conspirators a lot of the time, where we realised, 'Shit. Maybe we just need to do it.' We know what needs to be done, maybe we just have to do it and then realising that you need to step into that role and challenge yourself and your own understanding of your abilities. [LEx Leader]

4. Conceptualising Lived Experience Leadership

In this section of the road map, readers are asked to consider how it is that people with LEx decide to get involved in the organisation and planning of mental health care, how they want to contribute to change and ensure better levels of care and treatment for others.

This section outlines findings on how participants view LEx leadership, what it is and the values, qualities and skills that are important for leaders to have influence and impact. These findings are described in the context of the value proposition of LEx leadership: that it has vital functions to play in the transformation of services and integration of LEx across systems at all levels, including decision making. A further focus in this section is how leadership is linked to recovery, and why this link is important to clarify.

As another part of the project, we have developed *The model of lived experience leadership*. This model brings together the values, actions, qualities and skills that were identified throughout the project. These are summarised below.

Talking about leadership

> ***I think what a leader is in this arena is a change agent and I think because of our experiences, which I can generalise, and a lot of the negativity around that, we want to make a difference, we want to change, we're reformers and we're advocates for transformation which is a particular style of leadership, a model of leadership which has its own challenges. [LEx Leader]***

A broad view of leadership was used throughout the ALEL project, honouring the possibilities offered by a social movement perspective. Generally, this sees leaders as operating across informal and formal contexts and engaging with others to build local networks across dispersed groups, where power is shared and collectively harnessed. Leaders in these environments work to frame and shape public narratives about injustice and the difficulties faced by group members, offering a vision as well as solutions. Social movement leadership also identifies important processes of reorienting inadequate scientific perspectives to be informed by LEx, as well as building relationships with allies who have influence and access to resources, platforms and decision-making power (Brown et al. 2004).

Given this context, all participants were asked in the research about how they would define LEx leadership and to identify the values, qualities and skills of effective LEx leaders they knew. A thematic summary of their responses is below.

Values qualities and skills identified by LEx leaders

Roles and capacities
stands up - speaks up - understands unique and collective experience - creates space for others - offers connection and support - empowers others - promotes healing and recovery - strategic to mobilise - builds networks

Values
mutuality - equity - justice - citizenship/recovery

Qualities
authentic - passionate - persistent - honest - has integrity - hopeful - empathic - respectful - reputable - vulnerable

Skills
has influence - effective communicator - works big picture - works across sectors, groups, networks in personal and public spaces - keeps LEx lens/perspective - learns lessons

Values qualities and skills identified by sector leaders

Roles and capacities
advocates for change - shows initiative - articulates and identifies solutions - role models recovery - challenges others - creates space and provides support - gives purpose and meaning - strategic higher - level capacity - operates in complex policy environments - offers positive messages to community

Values
Fairness - human rights - empowerment

Qualities
Strives for change - passionate - charismatic - empathic - authentic - respectful/respected - patient - courageous - confident

Skills
Has influence and persuasion - effective and safe with personal stories - offers LEx perspective - operational skills - works across informal and formal spaces - builds good relationships - has self-care skills

I think they need to be incredibly patient with often archaic slow moving systems, and I think that it really helps if they have a good understanding of the sector that they seek to influence. [Sector Leader]

Together, these two tables reflect existing understandings about LEx leadership that are found across the emerging mental health literature. When combined with the last section on challenges and barriers, the feeling that LEx leadership is complex and often messy is obvious. It is founded on bringing in voices and key messages that do not easily align with professional paradigms, and also involves creating supportive spaces for these disruptive voices. LEx conveys themes, testimony and experiences which can be uncomfortable for helpers to hear and respond to, while navigating complex policy environments and competing priorities when trying to create space and have influence. LEx is political work, in the sense of influence and decision making, yet occurs in contexts that emphasise clinical evidence and authority.

Some different trends in responses across the mental health and suicide prevention spaces were observed: people talking from a suicide prevention network perspective often emphasised the personal and informal nature of leadership activity and community focus, while those operating in mental health environments only, mostly spoke in the contexts of health organisations, programs and established roles.

1. We want LEx leadership that rises out of our lived experience and reflects our unique learnings and experiences; 2. We want leadership that is built on difference, creativity and deep participatory democracy; 3. Horizontal power (not hierarchical power), shared networks, full consultation, and networks of shared leadership roles. [LEx Leader]

Recognising Aboriginal and Torres Strait Islander health leadership

Aboriginal and Torres Strait Islander people have a different way of understanding mental health LEx and have established organisations and frameworks of leadership. There are also conceptual understandings of social and emotional wellbeing, trauma experience and suicide prevention guiding the activity of leaders and programs.

The National Aboriginal and Torres Strait Islander Leadership in Mental Health (NATSILMH) group are senior leaders that provide advocacy and guide work across social and emotional wellbeing, mental health and suicide prevention. Their vision and statements relating to The Gayaa Dhuwi (Proud Spirit) Declaration are important for the LEx movement to engage with.

National policy in terms of the *National Strategic Framework for Aboriginal and Torres Strait Islander peoples' mental health and social and emotional wellbeing 2017-2023* help guide leadership and expectations for partnership. Locally, SA Health guidelines on Engaging with Aboriginal people and the Aboriginal Workforce Framework 2017-2022 offer important context and understanding.

The Aboriginal and Torres Strait Islander Lived Experience Centre has established a national network and also coproduced a working definition of Aboriginal and Torres Strait Islander LEx. The network consists of advocates and advisors working to shape service design and delivery, including support for codesign of suicide prevention programs in mainstream organisations. The centre has a focus on best practice and evidence-based approaches.

The Healing Foundation is a national Aboriginal and Torres Strait Islander organisation which provides leadership and partnership with communities in responding to the impacts of intergenerational trauma relating to the Stolen Generation. The foundation supports innovative work which brings Aboriginal healing concepts and knowledge, community preferences and western trauma knowledge together. Specific healing strategies for men, women and communities are developed.

In South Australia peak body health leadership is provided by the Aboriginal Health Council of SA (AHCSA), which represents the states network of Aboriginal Community Controlled Health and Substance Misuse Services. AHCSA also lead vocational education pathways in Aboriginal primary health care qualifications.

How LEx leadership is linked to recovery

It has been really beneficial for recovery but the boundaries and the accountability around managing my wellbeing are very, very much part of that leadership role and very important to be able to maintain [LEx Leader]

How it impacts on your recovery depends largely on what is important for your recovery. If things like meaning and purpose, connectedness and self-efficacy are meaningful and important, then it is likely to have a positive effect on those. That said, in both settings, the demands on your time and the personal and emotional nature of the work can have negative impacts, as can microaggressions from other workers and stakeholders, lateral violence and the stigma and discrimination that come with publicly identifying as a person with lived experience. [LEx Leader]

LEx leaders were asked how their activity and commitments in the LEx space impacted on their personal recovery. This link is not often raised in the Australian LEx movement as it is primarily about inclusion, justice and reform, not the recovery of leaders. However, it has long been established in the empowerment movement in the United States, that consumer led spaces create pathways for personal empowerment and recovery, which in turn encourages and engages people in some type of leadership. If recovery is social and outward looking, then it's intrinsically linked to leadership activity.

Some of these links were validated by this research. In summary, people with experience of LEx leadership reported:

Rewards and gifts
Being active generates meaning and purpose and enhances acceptance, honour and dignity of the LEx journey.

Relating to and supporting others also encourages self-accountability through walking the talk.

Empowering others often entails actions which contribute to self-empowerment, including the need to 'stand tall' in your experience.

Ongoing challenges
LEx leadership is difficult yet often highly rewarding.

Multiple stresses, demands, exposures and dilemmas can be experienced. Peers are often reminded about trauma and injustice, exposed to clinical, objectifying or deficit conversations, or feel contradictory demands of representative roles.

Some worry about their acceptance in the LEx movement and the different personal/public boundaries they experience.

Frustration and burnout due to slow change, seeing co-option or feeling unsupported by organisations are common experiences.

A common way of describing it
Being active as a leader is positive for recovery, when the right range of supports, networks and shared commitments are in place.

Summary

What I guess I found is by stepping into this space and trying to share my story, it's allowed for acceptance, it's allowed for me to be able to start trusting myself again and it's also been able to, I guess, raise the platform that I'm able to speak from or launch from. So rather than coming from a place maybe of shame and guilt and embarrassment, it's more of a place of this is my journey, this is my experience, these are my challenges and this is how I overcame that. So, there's a lot more I'm able to stand [for] in a positive sense, as opposed to in darkness. [LEx Leader]

This section has focused on a conceptualisation of LEx leadership, based on the findings of the project. It has highlighted that the experience of being a LEx leader, in seeking change and in navigating many challenges and barriers, is complex. It has also emphasised the different values, qualities and skills that leaders bring to and develop in their work.

One of the key themes of LEx leadership is transformation, and it is possible to see this potential in a number of ways. One is that people often come to be involved after experiencing personal transformation in their own recovery experience and want to share this with others. A further level is that LEx leadership influences transformation of systems, as there are multiple aspects of our current helping systems which are disempowering, and present very real barriers to the aspirations of the LEx recovery movement. This is where LEx leadership and change needs to be understood in the context of structures, relationships and mental models which maintain the current system.

For these reasons, it is important to articulate the following value proposition for LEx leadership. This has been forged from the findings above and helps to generate focus and clarity.

The value proposition of Lived Experience Leadership

We see LEx leadership as central to high quality mental health reform, governance of services and delivery of programs and services.

LEx leaders offer insights, understandings, connections and initiatives which are essential for enabling organisations, programs and services to empower people and families using services to move forward in recovery and citizenship.

LEx leaders work across multiple roles and spaces, within advocacy, management, community work, peer support, education and research.

LEx leaders offer multiple messages and value:

For existing services and colleagues in mental health, LEx leaders shape thinking on recovery, truly trauma-informed practice, inclusion, accessibility, equity, safety and quality of programs and services.

For peers and families, LEx leaders shape thinking and share expertise on recovery, hope, help seeking, service use, citizenship and being an agent for change.

For communities, LEx leaders are able to organise, manage and deliver services and programs based on methodologies of shared learning and peer support.

For systems, the calculated return on investment for every one dollar invested into peer support has been calculated at $3.27 (KPMG & Mental Health Australia 2018) and organisations embracing person-centred care has benefits in the areas of experiences of care for people accessing support, improved worker morale and wellbeing and better health outcomes. It saves the service money (Australian Commission on Safety and Quality in Health Care 2018).

LEx leadership is essential in our society overcoming the historical legacies of disempowerment, stigma and othering. These endure as a basis of community narratives, media and decision making around who people living with mental health issues are and what they can become. Transformation in these areas needs to occur across clinical practice, service reform, governance and media.

The personal transformation of recovery that has been a catalyst for LEx leadership, advocacy, education and peer support, can also inform a transformation of organisations and systems. We have the opportunity for ensuring our future services and organisations are truly empowering and supportive.

Effectiveness as a leader is not solely attributable to having LEx, and nor should the category of LEx be used in tokenistic, ideological or exclusive ways. Rather, effective LEx leaders stay true to peer values of justice, mutuality, equality, openness and empowerment, and express high-quality communication, interpersonal and reflective skills for the benefit of the broader community of people who experience mental health issues.

I champion for the underdog, the unheard, the vulnerable, the ones who can't speak out. From my own experiences I am passionate about changes to improve the treatment, care, stigma, discrimination and understanding of peers with mental health challenges and emotional distress. [LEx Leader]

I think it's certainly something that I think is important within an organisation. I guess, the power is in the word and the recognition and I think it adds something to that pool of experience and skills that we have in the leadership group if there is I think that designated role where…it is recognised that one of the things that person brings to the table is that lived experience, rather than it being, I guess subtle or unstated. It's a statement that says we value lived experience all the way through the organisation, so, not just in that delivery of services, but in our leadership group where we, I guess are influencing more around policy, process, strategic direction of the organisation. [Sector Leader]

5. Important considerations

This section of the Roadmap details a number of central considerations for how LEx leadership is framed, understood and acted upon. These include the common values that leaders bring to the table, the key concepts of epistemic justice, intersectionality and allyship, and the scope of LEx leadership within designated and non-designated roles. All of these elements were present in the project, and frequently discussed within the focus groups, sector leader interviews and Community of Practice.

The Roadmap recommends readers develop an understanding of each of these considerations and reflect on how these are being expressed in the initiatives they participate in or lead. We also offer a number of spotlight examples to consider LEx leadership and diversity.

The values base of human rights, citizenship, epistemic justice, equality and dignity

A key basis of LEx leadership and involvement is the values base that a person with LEx of recovery brings to their action and organisations. The recovery story and experience is incredibly valuable personally, and when shared with others in the peer support context. Realising that LEx was valuable was a key reason that some of the research participants entered advocacy and/or peer work.

Recovery is generally a positive and hopeful place to speak from. The presence of LEx leaders, however, also highlights the social context of struggle and injustice that can be reflected in many people's personal journeys. In terms of the research, these themes were about experiences of:

- Stigma, discrimination and othering surrounding spoilt identity.
- Losing dignity and being invalidated by helping services and systems.
- Trauma while in formal care services.
- A lack of decision-making power respective to helpers and for some, difficulties via the impact of diagnostic, reductionist approaches to mental illness and treatment.

Each of these themes were present in what many LEx leaders told us about the challenges and barriers associated with LEx work, in terms of the values base they were motivated by and in the experiences they often had in advocacy, education and employment contexts. In terms of values and commitments, LEx leadership is about:

- Ensuring human rights for inclusion, fair treatment and an end to coercion and trauma.
- Citizenship and inclusion: challenging stigma and othering by seeing LEx as a valuable, affirming identity, and that recovery is achieved through reconnection and empowerment as citizens (Stratford et al. 2019).
- Restoring dignity as the core of helping relationships. Championing peer support and peer methods which are based on validation, affirmation and belief.
- Epistemic justice: LEx is valued equally to learned knowledge. This recognises that different ways of forming and expressing 'knowing' are valued and validated by different parties, challenging assumptions of irrationality and unreliability (Newbigging & Ridley 2018).
- Mutuality as a basis of peer to peer relationships and should inform peer/clinician relationships.

Many participants shared insights and examples of challenges associated with working to express these values in organisational and policy settings. From the themes listed earlier, these include:

- Various stresses, exposures and inner work that come from engaging with psychiatric definitions, the medical approach and working in the best interests of consumers (rather than expressed interests). This presents ongoing dilemmas requiring processing and the need to 'stay peer' in this.
- Teams and managers not understanding the 'change agent' lens and positioning of LEx. A LEx leader pushing 'too hard' at a committee and expressing frustration might receive questions about their mental health or exclusion because they are 'too challenging'.
- Stigmatised assumptions about the capabilities of people with LEx, in terms of skills, capacities, limits etc., and how they can be trusted as leaders.
- Isolation – many positions in LEx leadership are unique in nature and limited in numbers. This intrinsically reduces power and presence within organisations, teams and decision making.

A systems perspective requires all of us to consider how LEx leaders can be better recognised for the values, critiques and aspirations they bring to organisations and policy work. How does the sector create space for and respect their presence?

> ***I think there's a real temptation in organisations to…conforming, to trying to look and act just like all the other professions and act as clinical or corporate as possible to fit in and be recognised as one of them. And that there can possibly be a risk there of sacrificing your authenticity to gain that influence and that position, and the need to be vigilant of also that similar risk of co-optation, and possibly the risk of losing sight of the social justice foundations of lived experience activism as well. [LEx Leader]***

Consumer and carer perspective

The ALEL project used a broad view of LEx leadership inclusive of consumer and carer perspectives. This was done as the focus of the work was on identifying suitable approaches for systems change and to recognise the work of leaders in diverse positions and settings, including the LEx workforce and in suicide prevention. We do note that this research and community development activities draws predominantly on the perspective of people with personal LEx who provided a consumer perspective.

Consumer leaders would likely point out that there are difficulties and ethical issues if the umbrella term of LEx conflates the distinct perspectives of consumers and carers. It is essential that this distinction is recognised whenever practices of leadership, coproduction, representation and activity are planned, so that spaces and roles are created for each group. This ensures that consumer leaders speak to consumer perspectives and carers represent carer perspectives, and one does not suffice for the other, recognising that a person cannot or should not represent both perspectives at any one time even if/when they identify as both a consumer and a carer. This clarity and commitment are required for many people in the LEx space who have personal experience of distress as well as caring roles, and for non-LEx leaders. ALEL promotes the principle that consumer voice and perspective needs to be primary in decision making.

Intersectionality, distress and disadvantage

The definition of intersectionality reflects its history as an academic concept:

'A theoretical approach that understands the interconnected nature of social categorisations – such as gender, sexual orientation, ethnicity, language, religion, class, socioeconomic status, gender identity, ability or age – which create overlapping and interdependent systems of discrimination or disadvantage for either an individual or group' (State of Victoria 2018).

This concept and practice is important to understand within the LEx movement. It helps us to recognise that:

- Our service systems reflect existing dynamics of power, privilege and disadvantage that are active in society. Services systems can unintentionally reinforce existing disadvantage by the way decision making directs the flow of knowledge, opportunities and resources. These dynamics can be transformed at different levels of systems by being conscious of them, working for inclusion, and empowering the involvement of disadvantaged groups in a substantial and meaningful way.
- That people and groups simultaneously experience membership of overlapping experiences, social characteristics and identities. Individuals and groups can experience multiple forms of disadvantage and discrimination on the basis of gender, Aboriginality, ethnicity, sexuality, geographic location, age, ability, and socioeconomic status (and others) that overlay each other and enhances complexity.

I often get into projects, because I tick so many boxes. So (intersecting identities), like and then, you're also – because they accepted you on to projects for all of those things, you're expected to be the resident expert on – and keep raising issues about every single thing and then if something comes up down the track and they say oh well, you didn't bring that up. And it's like well, I was trying to raise topics about four other things, like it's a bit – you're expected to be their whole answer to everything. [LEx Leader]

I think part of the reason why we don't say no as often as we should, is because we're afraid if we do say no, then that perspective will be excluded from whatever we're invited to, that they won't find somebody else that can contribute…and we want to be able to represent our distinctive communities and be that voice. [LEx Leader]

SPOTLIGHT
Aboriginal Youth Peer Specialist Positions

Sonder has recently established Aboriginal Youth Peer Worker positions within its headspace centres. This process has been a collaboration with the Adelaide Primary Health Network, who have identified gaps in access for Aboriginal young people and have provided funding for the positions. As part of a larger project, the positions aim to support cultural safety and responsiveness for young people accessing headspace centres, as well as strengthen the Aboriginal Youth Peer Workforce.

Intersectionality needs to be a key concept guiding thinking and action in LEx involvement, coproduction and system reform spaces. The following questions were asked during the project and discussed during focus groups and our community of practice:

- Does our understanding and operationalising of 'mental health/illness' restrict the wider social context of psychological injury, trauma, oppression and loss that is obviously linked to the distress experienced by many people within mental health services? If we are only centred in mental health and illness, as within the person, how are we able to address overlapping social stresses, determinants and barriers? Can we see 'mental health' within the life issues of homelessness, income stress, drug and alcohol use, cultural exclusion, and transphobia?
- How do the roles and settings created for and by LEx leaders enable recognition of intersectional experience and disadvantage? Do consumer representative roles and committee conversations recognise that people may have multiple aspects of relevant experience to offer? e.g. mental health challenges, poverty, homophobia, developmental disability? How do invitations for involvement and coproduction enable space for diverse groups to be involved?
- How do we organise for LEx leadership within different cultures and community groups? Many CALD groups may not have a language of LEx concepts, recovery, and suicide prevention, and the topics may be highly sensitive. How can the movement be more inclusive and supportive of Aboriginal health leadership, recognising the unique contexts of LEx relating to cultural identity, colonisation, intergenerational trauma and justice?
- How do designated LEx roles across the services system: within mental health, LGBTIQ+, alcohol and drugs, corrections, and family support relate to and acknowledge each other? How are individual peers with intersectional experience able to utilise the experience they wish to?
- How can limited resourcing of specialist peer workers (e.g. LGBTIQ+ mental health peer positions and/or cultural peers) be accessible to people across diverse geographic locations?

These questions do not have easy answers, but they encourage reflection on the arrangements and actions that are routinely done within services, and research. Part of the response is building awareness of intersectionality, seeing the limits and barriers that are often imposed unintentionally through actions, developing relationships and networks across diverse groups.

I think that to get diverse voices you need diverse opportunities and diverse mechanisms for engagement. [Sector Leader]

SPOTLIGHT
South Australian Rainbow Advocacy Alliance (SARAA)

SARAA is a leading advocacy network for LGBTIQ+ community inclusion, health and safety in SA. SARAAs broad focus includes advocacy within health care, law reform, religious practice and suicide prevention. Its community engagement work promotes awareness through campaigns, and local research and leadership development.

SPOTLIGHT
PEACE Multicultural Services

PEACE offers a range of innovative services and programs using community leadership and empowerment principles in working with diverse community groups. Many projects aim to build community capacity to address health and wellbeing issues which relate to sensitive and challenging topics. These include developing responses for gambling help, family violence and preventing or living with blood borne viruses. PEACE uses peer learning approaches for helping community members develop better literacy, knowledge, confidence and support pathways. PEACE peer workers also offer feedback to funders about community members' experience of service and the ways in which funded programs can be more flexible, responsive and effective to diverse client needs and preferences.

Allyship

Allyship is a justice based social movement idea that accompanies a focus on intersectionality and inclusion. Allyship involves understanding your own positioning, privilege and relationship to the person or group you are working or advocating with. Allies do not visibly share the specific LEx of a group, but play key roles in supporting the advancement of the group's interests. Allies work on:

- Recognising, validating and supporting LEx groups and/or their advocacy interests within decision making.
- Creating spaces and opportunities for the group to be involved, heard and supported (Happell & Scholz 2018).
- Enabling access to resources, funding and decision makers.
- Acting from the principles of empowerment; staying in the non-peer space and not speaking for LEx. Understanding their own place of privilege and acting on this.
- Working at different levels, e.g. organisational and policy/systems level to support goals for change (Happell et al. 2018).
- Role modelling allyship, having influence horizontally for other potential allies (Byrne, Happell & Reid-Searl 2017).

A person's positioning in allyship can be fluid and dynamic, having membership with one/some disadvantaged groups but also being an ally with others. An example of this is below.

Example of allyship

A mental health team leader may be same sex attracted and may have a daughter who is living with autism. She may also have a brother living with psychosocial disability. She has LEx as LGBTIQ+ and with caring in two different disability spaces. She can position herself as an ally for people with personal LEx in the psychosocial and ASD areas, or other groups she is keen to support. Within the LGBTIQ+ community she may be an ally for the advocacy goals of trans people. Within her work setting, she can generate growing awareness and opportunities as an ally, depending on her personal boundaries and whether wider aspects of her identity can be appropriately expressed in this way. As allyship entails creating awareness and space for power shifts, she will have dilemmas about challenging colleagues and management, when to advocate, and what expectations to set with LEx groups. This experience of allyship is likely to be easier if everyone in the organisation understands the importance of working towards recognition and inclusion.

People with lived experience in non-designated leadership roles

How do people in non-designated roles with LEx of mental health issues or caring contribute to LEx leadership? This was a common conversation in the focus groups and interviews. Participants frequently indicated that mental health teams and organisations often have higher numbers of staff with LEx, yet often those staff with LEx have not disclosed this and therefore are not 'out' nor operating from that paradigm in their roles and working life.

People shared that there were personal risks in coming out and being othered. In situations where they had disclosed their LEx while functioning within generalist roles they had experienced disempowering commentary from colleagues and others about the validity of their LEx. People living and working in regional, rural and remote areas face additional challenges in coming out, and how their story is heard or implicates others.

> ***Some of the best lived experience leaders that I know wouldn't identify with that label, and their lived experience is often silent, but their perspective that comes out of the leadership table you can tell comes from that genuine place of having a lot of empathy and people who have actually – they're not just walking in other shoes, they've walked in those shoes, so they really get it. [Sector Leader]***

This area raises many questions and dilemmas, especially when prescribed guidelines are not in place. People are encouraged to continue to wrestle with the issues, especially taking a perspective of how people can be 'out' and/or an effective an ally. Some other considerations when people in non-designated roles disclose are:

- Work on advancing the level of general LEx awareness and involvement in your organisation – as an ally speaking on the level of principles, issues and frameworks, and creating space for others.
- Recognise that many LEx opportunities are specific and should be filled by consumers and carers who have direct experience and voice on the services, experiences and diagnosis under consideration. This ensures LEx is qualified and context specific.
- Be a part of using your LEx in general forums and connecting with advocacy efforts of peak bodies and systems change efforts outside of the employment context. Acknowledge personal LEx and allyship, as well as your place of privilege in this. Develop a connection with collective consumer perspectives.
- Work on ways to use public forums, messages or writing on the themes of their own LEx. How these relate to relevant practice reform, change, or the development of frameworks relevant to their professional identity (e.g. trauma-informed care) can be powerful.
- Be careful about the lens and messaging that is used: wearing a LEx 'hat' at the same forum as a professional clinical 'hat' is confusing. Separate them out, as it's very difficult to have both hats on at the same time. Clarification and qualification of speaking positions is essential.

> ***As soon as I started, I guess it was important to me to be transparent about my own lived experience. And I think for the peer workforce, that was valued, and that I had the confidence to do that, but it was just ignored in the organisation…There was no structures or culture for it to be understood or recognised or valued in any way. I didn't feel it was problematic for me, but it just bounced back. It was like Teflon, it just bounced back…I hadn't experienced in the (time) that anyone else had been transparent or open about that identity, but it was just kind of sat there and then ignored really. I think part of it, and I'm just guessing, was that rejection of my identity around that as in well, you can't really have lived experience because you wouldn't be in this role if you did or you know? I think that was part of it, a bit of a disbelief of the genuine and the integrity around that. And part of it was just not knowing what that means in a leadership capacity, so not knowing what to do with it. [Sector Leader]***

6. Knowing and supporting LEx leadership

This part of the Roadmap encourages readers to consider the role they can play in contributing to change. There are various audiences involved and different environments for activity.

LEx leaders

The understanding of LEx leadership gained through the ALEL project and the team's own immersion in the lived experience community as individuals highlights that declaring and using LEx is about taking initiative and leading change. It's not necessarily about the specific LEx role held, since being in a role doesn't automatically mean that leadership is demonstrated. Leadership can occur regardless of the role or positioning people are placed in.

This research found that people using LEx for change often do not equate their work as leadership, as it is an emerging concept within the wider movement. Existing notions and models of leadership may not easily fit with people and be assumed to be about management within organisations, patriarchal values, or power over others. For this work, it means that there is work to do in developing a shared and inclusive concept of LEx leadership and for diverse communities to engage with this concept.

> ***I find it, I guess, difficult to define leadership in a way because I just don't see myself as a leader. I'm just a (description) dag who's very big on community responses. And I think that's part of what leadership is, if you work for too long, this idea that it's about you get up, you share your story and collapse. And you get the thumb, 'Yay, good on you,' when in reality it's often we're the ones who are bringing the collective experiences of people living with the stress of people who access services for support into conversations that they've been excluded from for a very long time, such as policy development, program development, service structure, that sort of stuff. [LEx Leader]***

Research participants shared that leadership is meaningful if it is effective, true to peer values and works for the big picture. LEx leadership needs to be horizontal and collective, avoiding hierarchies. This reflects the values of mutuality, respect, empowerment and justice, as well as the different relationships and networks of LEx. In promoting systems change, there is a need for members of LEx communities to work effectively together, and to work through the diverse preferences that occur within the movement, and the dilemmas that can be involved. People also shared that lateral or vertical violence can occur, that powerful positions can be protected or used in the wrong ways in responding to conflicts. Leadership also occurs in the context of lived experience groups operating within distinct diagnostic or specific interest areas, or groups operating within specific age, cultural and geographic areas. Taking a big picture perspective helps the LEx community acknowledge the leadership of others, where collective values can be used to guide our relationships and problem solving.

> ***I see the leadership being across organisations and being above organisational wants and desires and things, a bit more of a collective community. And I think that leadership is that person who brings all of the different parts of lived experience together, who builds those networks, and I also think it's about who is strategic and thoughtful in how we can mobilise. [LEx Leader]***

> ***I think it's the difference between working from your head only and working from your heart as well. [Sector Leader]***

SPOTLIGHT
examples on lived experience led groups

Bfriend

Bfriend is a community development program with Uniting Communities offering peer support and counselling for people who are newly emerging as LGBTIQ+ and builds community connections. Bfriend has a workplace training program, coordinates an information service of LGBTIQ+ drop in and support groups, and organises a volunteer group of peer mentors.

Whyalla Ripples

Whyalla Ripples is a support and information group with a focus on supporting family and friends who are affected by personal use of ice or who are in recovery from ice addiction. Peer support and learning play a major role in creating support networks in regional cities.

SPOTLIGHT
examples on lived experience led action

South Australian action plan for people living with borderline personality disorder (BPD) and BPD Co:

The BPD Collaborative has been developed in South Australia in response to repeated consumer and carer concerns about the availability and quality of the effective services for people living with BPD. This includes the need for improved awareness, understanding and compassion within helping responses. Consumer and carer leaders played a central role in working with government and clinical leaders to develop policy responses such as the BPD Action Plan and in lobbying to gain funding for eventual services. LEx leaders continue to provide support via local networks, support groups and in project management. Carer leaders have also established Sanctuary, as a successful and growing carers support group.

Batyr

Batyr is a peer-based program that encourages young people to challenge stigma, raise awareness and encourage help seeking through the use of LEx and personal stories. The program organises workshops within schools, universities and workplaces and provides training and support for peer speakers.

Executive leaders and policy makers

The project identified executive leaders and policy makers as well placed to create changes within systems. Making key decisions about organisational development and strategic planning, or shaping commissioning and policy development, means that leaders in these spaces are able to initiate shifts across structures and relationships. Leaders can also set the tone for transforming the typical assumptions about consumer capacity and expertise within decision making. Each of the eight key actions of the Roadmap conveyed later in this document have direct relevance for organisational and policy leaders.

> ***Even if I'm at my most generous and feeling that generally the ideology is valued, it has no reflections that people in positions of power need to let go of that power or share that power. It's just there's a long way to go. And one way of potentially doing that is to be deliberate around creating space and value for lived experience leadership, because I have no doubt many of my colleagues have their own experience. [Sector Leader]***

Allies in the workplace and community

As described in the previous section, the role of local champions and supporters of LEx leadership is essential for achieving shifts at local levels. Team leaders, clinicians, workers, human resources and finance managers all have a role in recognising and supporting the success of new positions and opportunities. Allies contribute to facilitating people with LEx connection to networks, helping emerging leaders grow in skills and confidence, identifying resources, and connecting them to decision making opportunities. Following are some reflective questions for each group to consider.

> ***We are a decade into the integration of a lived experience workforce into mental health and we sometimes feel we're no further along that road than when we, kind of, started, and that to me is indicative of those hidden barriers that we have a responsibility to recognise within ourselves and to work on those and to support people into the roles that are important. [Sector Leader]***

LEx leaders

What contributions can I make to influencing organisational and systems policy?

Can I improve the way I contribute to submissions and coproduction efforts? Can I support others to get involved?

What skill development would I need to sit on a council or board of management?

What networks do I both belong to and support as an ally?

How do I work through dilemmas that I have with others in the LEx movement? How do peer values establish common agendas for change?

How am I involved in mentoring and supporting others?

How do I see my own personal power and ways I can progress empowering narratives about LEx and recovery?

Executive leaders

How can recognising LEx leadership become an organisational priority in terms of government, service reform, workforce development and supporting LEx pathways and networks?

How do we redirect our resource flows to LEx leadership and coproduction?

How will executive decision making and planning be improved by strengthening LEx perspectives within this?

What can I do to encourage buy in and commitment towards LEx leadership across organisational stakeholders, partners, and funders?

How can we challenge client/provider assumptions within our organisation that are disempowering and limiting for people with LEx?

Allies and supporters

What organisational and team-based shifts can we make to ensure we coproduce local services, programs and activities?

What local leadership opportunities, including team leader positions, can be designated peer positions?

How can we develop effective pathways that help LEx leaders be successful and not set up to fail?

How does our team build ally relationships with diverse groups and have an intersectional focus?

What regular events and network meetings do we commit to on a regular basis?

How can we create a culture, where the wider workforce is open about their LEx and supports the work of people in designated peer work, and representative positions?

How can we be vigilant in overcoming 'othering', and support people's aspirations for change?

Policy Makers

How do we ensure our population planning and policy occurs through coproduction?

What leverage can be built into funding requirements for better recognition and accountability towards LEx leadership?

Can our commissioning establish a specific funding stream for LEx led organisations and programs?

How well does our policy unit build relationships with a variety of LEx voices? (cultural, identity, political)

How do we communicate with other stakeholder groups, professional peaks, unions, and private sector leaders about the valuing of LEx leadership?

What opportunities and spaces can we create for LEx policy leadership?

How does our narrative promote an inclusive, citizenship-based perspective on mental health, illness and wellbeing?

7. Systems change – identifying strategies for structural, relationship and mindset shifts

The literature on systems change emphasises the importance of identifying strategies which can have an impact over multiple levels, realising that actions can be formulated across:

1. explicit structural features, such as policy, practice and funding, in
2. relationships and decision making power and
3. in the mental models and cultures of mental health.

This Roadmap for change has covered a lot of territory, highlighting that LEx leadership is emergent and faces numerous challenges and barriers from the organisational and cultural settings where it occurs and where it seeks change. LEx leadership also expresses values based on justice, human rights, equality, recovery and citizenship and brings these values to offer critiques and possible solutions to exclusion and negative systems impact for consumers and families.

The Roadmap also describes important considerations that shape or should shape how LEx leadership is enacted, recognised and supported. These include working from an understanding and commitment to intersectionality and allyship. Potential contributions of the non-designated workforce with LEx have also been discussed.

What does LEx leadership need to thrive and have impact?

The question about what LEx leadership needs to thrive and have impact was asked throughout our research and leader interview processes. This question sought discussion of the high level actions that are needed within organisations and at the systems level, covering policy and commissioning, decision making and the flow of resources, executive leadership, frameworks for guiding organisational change, and the pathways for involving LEx leaders. Analysis of the data and resulting themes show that there is considerable overlap in the perspectives of LEx leaders and sector leaders.

We need power. And recognition.
[LEx Leader]

We need people to actually commit and say, 'This lived experience leadership stuff is valuable; we're going to put some money at this and make sure that it happens, and it happens properly.' [LEx Leader]

Two things at least. One is an open declaration from government that legitimises it, that says to the community that, when we talk about anything to do with mental health, that lived experience will sit around the table and be part of the decision-making process around it. So, there's that overarching policy structural systems legitimacy to it. But the other part that it needs to flourish is recognition, respect, trust within the sector that recognises that someone's professional views, because they're a social worker, are no more legitimate than someone's lived experience of having a mental illness. It doesn't matter whether they are a social worker or a psychologist or psychiatrist, whatever, that it actually sits people with a lived experience equally around the table at every local decision-making process as well…There's the trust and respect down in the ground and then there's the overall systems statement that this is – and not just the statement, testing of that statement to make sure that it is actually being pursued.
[Sector Leader]

What LEx participants told us

Following are eight themes which characterise the directions collectively identified from focus groups and the online survey.

Commitment to funding
Change requires improved commitment to funding initiatives which reflect or generate LEx leadership within organisations and across the system.

Obliterate stigma and tokenism
Stigma and 'othering' needs to be challenged through better public awareness and in mental health organisations. Genuine partnerships and processes of shared decision making need to be the norm.

Reformed models of care – recognising LEx practice
Reform should generate a scaling up of peer support workforces within teams and LEx led models of care, enabling consumers and carers to connect with authentic peer and recovery values.

Coordinated LEx leadership
The robust development capacity building of peak peer organisations and networks to enable voice and direction. Also include using collective, power sharing models of leadership. Providing support, tools and resources is a central role.

More leadership positions and higher influence
This includes more seats at the table of system and organisational decision making and lifting numbers of designated team leader and management positions.

Frameworks for better understanding and options
There is a need for improved sector wide clarity on LEx leadership purpose and associated roles/functions to enable non-LEx workforces to have better recognition and understanding, and to guide development of LEx pathways and effectiveness.

Sector leadership and valuing of LEx
Improved levels of respect and valuing of LEx should be demonstrated by sector leaders, providing through better organisational supports, better levels of transparency and accountability.

Intersectionality and allyship
The LEx movement, and roles created via LEx should reflect and encourage intersectionality and diversity. This includes how peer support, representative, advisor and educator opportunities are framed, and the numbers of opportunities available. Consideration also for CALD, LGBTIQ+ communities and First Nations Peoples' understanding and engagement with LEx concepts, and implications for members. Allyship is promoted as a central way of framing supportive relationships between and across LEx communities and individuals, and between people with LEx and non-LEx workers.

What sector leaders said is needed

Improved knowledge and infrastructure
This included embedded infrastructure for supporting LEx positions, including supports for ensuring involvement/partnerships in regional, rural and remote settings. More sharing of research evidence about effective organisational supports. The need for organisational strategic frameworks on LEx leadership, and ability to leverage resources across programs and local services.

Executive leader actions
Increased demonstration of trust, respect and recognition as leaders. Openness to change, the need for executive self-education. Demonstration of commitment to action and accountability to LEx communities.

LEx at higher places of influence
Recognise that LEx leadership influences politics, policy and funding, and executives can facilitate pathways and share platforms in these areas. Executives can use resources to create positions and opportunities within the workplace, boards and other governance structures.

Improve shared understanding
Ensure policy and standards initiate action and accountability. Encourage vision and growth of LEx workforce and leadership with goals and processes for change. Promote clear understandings of LEx designated purpose and roles and implement required cultural change to challenge discrimination and othering. Work across stakeholders and organisations.

Create LEx leadership pathways and supports (see below)
Better peer debriefing, mentoring and supervision supports. Promote specific coaching and training on leadership skills. Include focus on self-care and safety. Enable access to internal and external supports. Build on network models for bringing people together. Creating pathways and opportunities to nurture and grow emerging leaders. Work from intersectionality and diversity standpoint.

Networks and pathways development

The research work with LEx leaders had a very significant focus on perspectives about preferred developmental pathways and learning networks. This is a critical area for LEx action and leadership to thrive and have impact. Numerous questions were asked about these and areas of learning, preferred topics, and ways of offering training. Focus group and survey questions also asked about the differences between learning pathways for systems advocacy work and peer support work. The central themes from the analysis are below.

I think any leadership, and this applies to lived experience leadership, needs support and mentorship and encouragement and systems to facilitate it because if you are going to be changing things there is a set of skills that go along with leadership in whatever way whether it's advocacy or operational I think genuinely leadership roles benefit from having somebody outside of their own chain or reporting who hey can talk to and be supported in what they are doing. [Sector Leader]

It's being involved in systems change and I've just noticed that recently…there's been a lightness that wasn't there before and that something shifted and that's because it is about supporting the change of transformation and it's also about the collective community suddenly I'm in a...it's a horrible club to belong to if you know what I mean by that...but it's a wonderful club to belong to. So, I'm in a safer space than I was before because I'm more connected to these networks. [LEx Leader]

Networks for collective action and support
Improved networks are needed to connect local and emerging leaders, to enable a sense of collective leadership and mutual support relationships to help leaders share the load of advocacy and foster longevity in the movement. Strengthen existing networks, by connecting with active groups and improving public promotion and information. Informal and formal options are important.

Information network development
There is a role for a leading LEx organisation to strengthen information networks which promote leadership learning and opportunities, and events across diverse LEx groups. This requires network building and media expertise with an intersectionality focus.

Advocacy specific pathways
Advocacy within leadership requires specific learning and training including principles and skills of systems advocacy, as a skills base beyond peer support work. This includes networking skills, understanding how systems work, and skills for influence, identifying solutions, and being strategic. Visible and supportive pathways for becoming active and involved need to be developed. Advocacy work requires time and space away from other work.

Peer support work pathways
It is important that pathways for formal learning and qualifications are visible and easy to access. 'Apprenticeship models' can be helpful, and increase supports for learning. Overall career pathways for people in existing peer support worker roles to leadership-based roles need development, otherwise people gravitate to other 'professional' qualifications.

General and specific pathways
There are general values and skills that underpin the LEx movement which people working in diverse settings and activities could base their work on. There are recognised differences in working in either predominantly peer support work or systems advocacy roles, skill sets and learning pathways should be developed for each and be mutually informed.

Mentoring roles
Mentoring is seen as a central aspect of LEx leadership learning, with access to mentors needing better recognition and support by employers and systemic advocacy spaces. Often mentoring is informal, with people seeking aspects of experience from others. Training in how to be a mentor would be beneficial.

Coaching roles
Coaching roles were identified as being a focused and formal method of improving skills as a LEx leader. Some people may prefer coaching instead of mentoring as it is often a more defined process.

Peer based supervision
Supervision within employment contexts for peer support is an essential aspect of success. People can have mixed experience of successfully accessing peer-based supervision that is helpful. Internal and external options for supervision should be available to people and supported by management.

Preferred learning topics
Highlighted learning topics include: advocacy fundamentals, self-care skills, having influence, working with teams, working with emotions and conflict, sharing stories effectively, mentoring, supervision and coaching roles, effective communication, working in management spaces, managing up, network building, allyship, personal boundaries, responding to stigmatising communication, defining LEx.

Preferred delivery of learning/training
Preferences include: online availability – e.g. recorded zoom sessions, 15 minute short sessions as well as longer form of 2 or 3 hours. Important to ensure flexible access and timing, a skills sharing approach, and follow up learning/support. Other preferences include diverse learning styles and reflective practice and to ensure training is LEx-led. Payment of training encourages a sense of 'value for money' for organisations and individuals.

8. Identifying eight priority actions for change

Consolidation of research findings led to the formulation of a set of 18 actions which were explored and prioritised during the second System and Sector Leaders' Summit in February 2021 (Hodges et al. 2021a). After deliberation and a consensus promoting process, Summit participants agreed on the following eight priority actions for South Australia. These have been developed in an accompanying *Strengthening lived experience leadership for transformative systems change: A South Australian Consensus Statement.*

These actions, if followed through, will enable significant shifts across the service systems. If sector leaders and organisations continue to engage with these actions and consider the examples of shared outcomes/measurement, the work towards collective impact will be successful.

The next section outlines each action, and the types of outcomes sought. There are three directions indicated to illustrate different possibilities for change. The first direction is to fully invest in achieving the action, and what would happen if done to the best of the sectors collective capacity. The second path is to attempt change without careful consideration and take short cuts. The third road is for things to stay as they are, where some organisations are working in this area, and others not. This approach has been used to provide a picture of what is possible.

The eight priority actions are generalised statements that need to be seen at a systems level and a local level. How each community group, organisation and policy unit interprets them will depend on their particular setting, their current practice and the partnerships they have or are willing to build with diverse communities. This will include partnerships of local support groups and community initiatives, Aboriginal health organisations, multicultural services and programs, different towns and regional centres, youth sector and disability support groups.

As a Roadmap, the focus of the actions remains broad, and detailed strategies for implementation have not been provided. Spotlight examples have been offered as a way of connecting with a range of innovative examples of coproduction processes, peer led approaches, shared peer/clinical approaches and community initiatives from Australia and other countries. A number of existing frameworks for lived experience workforces give detailed strategies for organisational development, supporting networks, human resources, infrastructure and supervision. The spotlights are offered as examples and are not implicitly endorsed by the ALEL project. Leaders are invited to consider how they work locally and collectively to make progress in each priority action.

Policy and governance

Action 1

Increase the presence of LEx leaders in governance. Ensure more LEx designated director positions with boards, statutory councils and commissioning groups.

Action 2

Learning and cultural change programs of LEx leadership are arranged with executive leaders, staff and communities focussing on diversity of LEx leadership, supports, preferences and working through stigma and othering.

Outcomes if we do these well

Increased number of positions creates opportunities and pathways, complemented by improving skills of LEx leaders, and inclusive leadership skills of Chairpersons.

A critical mass of effective LEx leaders enhances quality of decision making and planning for better services and outcomes, increases accountability and communicates value to community.

Increased understanding and acceptance of LEx and the recovery approach is demonstrated within organisations and community groups.

Increased openness enables higher level of coming out and involvement.

Peer workforces and representatives report better acceptance, role clarity, feel valued and less isolated. The narratives we use to describe mental health are empowering and compassionate.

Things to consider

- Encourage diverse skills mix and LEx/non-LEx mix. Value all perspectives.
- Processes of governance support and resource the diversity of voice and presence of LEx leaders, including their links with networks.
- Should quotas be prescribed?
- Consider business planning approaches to increase influence.
- Requires nurturing of new and emerging leaders, and skill development.
- Strengthen best practice standards of governance, chairing and inclusion to be effective.
- Learning and cultural change programs need to facilitate shifts in attitudes, generate leadership and collective commitment.

If we take short cuts

Uncertain territory without developed facilitation skills, and safe welcoming Boards. Sets people and organisations up for failure.

If we stay in the same place

LEx leaders continue to go through frustration and burn out. Limited opportunities and pathways. Without momentum and focus new people won't be encouraged to join the movement. Quality of decision making and innovation remains limited.

SPOTLIGHT
examples on policy and governance

NSW Lived Experience Framework:

The NSW Lived Experience Framework was coproduced by the Mental Health Commission of NSW, stakeholders and experts with LEx of mental health issues. This resource demonstrates pathways to fulfill the call to embed LEx within the health sector in all aspects of service design and delivery. As an example of a state level document, the framework identifies and articulates the need for a collaborative cultural shift within services and organisations, guidance around inclusive language and provides guidance for placing LEx values and principles at the centre of all organisational change. Small grant rounds have been offered to organisations to support projects that support implementation of the ideas and actions contained within the framework.

The Queensland Framework for the Development of the Mental Health Lived Experience Workforce

The Qld framework's section on organisational commitment provides strategies on the various ways organisations can value and embed LEx voices and roles, and make changes to workplace culture.

Youth Affairs Council of SA

YACSA is a membership based, peak body for youth in South Australia that focuses on advocacy and representation. Its key functions are research and policy development, capacity development, information, and consultation. YACSA encourages membership of young people and requires at least two young members to sit on its Board of Management.

The Strong and Capable Cooperative

The Strong and Capable Coop in Adelaide's North is Australia's first cooperative owned, run and governed by people with disability. The Coop is focused on maximizing utilisation of NDIS plans and for people living with disability to live better lives.

Growing and nurturing LEx leaders: supports and networks

Action 3

Strengthen learning pathways and leadership skills development for people with lived experience and enable and encourage opportunities for them to lead and provide advocacy. Enable easier access to professional development and formal qualifications.

Action 4

Fund leading LEx organisations to develop and deliver networking activities, including coordination of information, activities and events that support local LEx leadership, community initiatives and voice across diverse population groups. Focus on intersectionality.

Outcomes if we do these well

A wider range of pathways and networks exists and are more visible and accessible.

LEx leaders are more skilled in systems and organisational advocacy and change.

Enhanced career pathways for the LEx workforce into designated or other roles.

Improved information networks, increased numbers of people informed, skilled and available for coproduction and advisory roles.

An intersectional focus brings people together to develop common narratives of mental health, distress, recovery and citizenship, in ways that are also meaningful for diverse groups. Culture, identity and wider life issues are better understood and inform lived experience thinking.

Leaders within community initiatives learn from each other and connect across South Australia.

Things to consider

- Some development opportunities can be linked to non-mental health existing training and education e.g., existing leadership programs.
- A number of LEx networks and organisations have a presence in South Australia.
- Funding for learning and networks needs to be adequate and sustainable.
- Develop an approach which maps networks, supports and mentors smaller groups and recognises uniqueness and diversity.

If we take short cuts

Pathways are developed, but are short lived and project based. They do not reach across the system to reach diverse identity and geographical groups. LEx leadership expands only in committed organisations or through the persistence of individual LEx leaders.

If we stay in the same place

Pathways remain difficult to identify and people learn about LEx and peer work by accident. Groups with LEx remain disconnected. Systems advocacy learning and collective leadership remains at low levels. The full potential of LEx leadership to influence at a strategic level and bring increased accountability to the system is not realised.

SPOTLIGHT
examples on LEx supports and networks

Leadership training

There are a number of examples of specific leadership training programs for people with LEx. A program operating for many years in the USA has been the West Virginia Leadership Academy (Stringfellow & Muscari 2003). The academy has supported the development of hundreds of consumer leaders since the late 1990s, with participants attending from different states. Leadership training occurs in the context of peer values, empowerment and systems advocacy, with graduates joining boards, committees and policy councils. Teleconferences bring leaders together to discuss their experience and advocacy achievements.

The NSW consumer peak body, Being – Mental Health Consumers, is current developing a leadership training program, in collaboration with the Nottingham Recovery College, UK.

The Yale School of Medicine's Yale Program of recovery and community health also has a LEx leadership training program, the Lived Experience Transformational Leadership Academy (LET(s)LEAD).

Consumer perspective supervision

The framework was developed to guide peer-based supervision for peer workers in Victoria. It was developed via a consumer led coproduced process. Key principles, contexts and pathways are covered by the framework.

National consumer supports technical assistance grants program (US)

For many years, the US Federal Government's Substance Abuse and Mental Health Services Administration (SAMHSA) has funded National Training and Technical Assistance centres to strengthen consumer leadership and support consumer run organisations. The funded centres work across regions and networks supporting training and organisational development in local organisations. This can include peer support training. The 2020 funding round provided grants to five centres including Doors to Wellbeing, YouthMove peer centre and PENTAC.

The Lived Experience Development Governance and Education (LEDGE) Project

LEDGE has been developed by LELAN to increase the capacity of emerging LEx leaders to be a part of decision-making processes and influence service governance. It offers learning opportunities and skill development pathways for both LEx leaders and organisations wanting to develop their capacity. For organisations, it's about building executive leader awareness, skills and knowledge so that committee/board environments are accessible, supportive and valuing of LEx perspectives and collaboration. LEDGE is funded by Department of Social Services to operate in the psychosocial disability context

The Mental Health Lived Experience Engagement Network (MHLEEN)

MHLEEN offers a learning network for Primary Health Networks (PHNs) around Australia to involve consumer and carers in the cycle of commissioning new services. It is overseen by Brisbane North PHN. MHLEEN also exists to develop the lived experience workforce and collaborate with different community groups and services

Rapid Enterprise Development (RED)

RED is an organisation which supports people with LEx of disability to engage with and develop skills and capacity in enterprise. This includes connecting people with opportunities, guidance and tools for business planning and self employment. It uses connections creatively so that a person's NDIS budget can support learning pathways and capacities for income generation.

Service reform and development

Action 5

Enable resource flows for meaningful coproduction of all services and programs. This should include training of coproduction facilitators and chairpersons, and funding equal places at the table for LEx advisors and leaders.

Action 6

Promote LEx leadership and accountability measures through service agreements, KPIs and, where appropriate, regulatory frameworks and legislative processes.

Outcomes if we do these well

All services and programs are coproduced and have better relevance for diverse community members, and accountability back to them. Trust is strengthened.

Dedicated resources are used to bring and support people with LEx in decision making settings, ensuring consumer and carer voices guide design, alongside clinical knowledge.

All mental health organisations have skilled coproduction leaders.

High quality coproduction processes and expectations are core business.

LEx leaders, clinicians and sector leaders report effective and genuine deliberation and partnership, power sharing, planning and evaluation. Conflicts between perspectives are heard and responded too, rather than remaining marginal.

Funded mental health organisations are able to report on and account for their achievement of collaborative leadership and shared service design. Human rights is a yard stick for evaluation.

Things to consider

- Resources invested in people, funding and time.
- Coproduction outcomes need to go beyond process outcomes of getting people involved towards improved services and wellbeing outcomes.
- Consider context of embedding within service and professional standards or commissioning processes.
- Accountability requirements should not be onerous, but demonstrable across organisations and the sector.

If we take short cuts

There will be improvements, but shared expectations and practices of coproduction won't be across the system. Lack of accountability measures mean inconsistent approaches by executive leaders, and reduced transparency with consumers and carers.

If we stay in the same place

Coproduction occurs in some settings and not others. Enduring issues of low and inadequate resourcing of coproduction continues. Uncertainties on language and commitments continue. Chances of experiencing disappointment and tokenism continue for people with LEx.

SPOTLIGHT
examples on service reform and development

Co-design: doing it in the real world with authenticity

An example of training for co-design skills is the work offered by the Australian Centre for Social Innovation (TACSI) in partnership with consumer academic, Indigo Daya. This is a 22 hour learning program occurring over 8 weeks. Participants learn about the concepts and conditions of co-design, establishing projects, methods of inviting and involving people, and prototyping new ideas.

Co-production: putting principles into practice in mental health contexts

This is a resource produced by consumer academics within the University of Melbourne focussing on the specific principles of co-production and how these can be articulated in contexts of planning and decision making within mental health. This helps readers to understand the importance of involving and empowering consumer leaders in agenda setting and as equal partners in expertise and planning. Co-production has an overt focus on power sharing, reducing imbalances and developing opportunities for consumer leaders to further develop skills and capacity.

Aboriginal Experts by Experience Register

All of South Australia's country based Local Health Networks (LHNs) facilitate involvement of local Aboriginal leaders via the Experts by Experience Register. The Register creates pathways and opportunities for leaders to advise on health issues and service design.

SA Urgent Mental Health Care Centre: Philosophy of Care

Before commissioning South Australia's new Urgent Mental Health Care Centre, the Office of the Chief Psychiatrist (OCP) funded LELAN and the TACSI to co-create a Philosophy of Care (PoC) with the lived experience community. This document was created to guide the eventual centres design, implementation and oversight, so that consumer and carer preferences for care experiences would be provided. Once complete the PoC was used to guide the tender process and grant allocation. The PoC is now being used as an underpinning document for the OCP's NGO Redesign Project.

Brisbane South PHN Commissioning

The approach Brisbane South PHN takes to commissioning local services has a significant focus on co-design. This includes co-designing the service model for mental health, suicide prevention, alcohol and other drugs with Aboriginal and Torres Strait Islander people, LGBTIQ+ and CALD community groups.

Workforce leadership

Action 7

Ensure models of care include equal recognition of LEx workforces and peer support.

Action 8

Ensure a range of organisational and sector infrastructure for the effective recognition, valuing and embedding of the LEx workforce.

Outcomes if we do these well

Revised/new services and programs will feature significant peer support work teams.

Increased availability of peer support workers to consumers, carers, families and kinship groups. This includes specialist peer workers within mental health as well as cultural peers.

Improved expression of authentic peer approaches to language, human rights and support within service models, aligning with consumer experience and preferences.

Organisations and individuals have improved access to effective infrastructure for support, including human resources practices, supervision models, coproduction practices, measurement processes. This includes organisational frameworks on LEx leadership, involvement and workforce development.

Peer workforces and representatives report better acceptance, role clarity, feel valued and less isolated. Vulnerability is understood as a strength and vital element of lived experience.

Improved career pathways for LEx leaders including designated team leader and management positions.

Things to consider

- There are examples of 50% clinical and peer models e.g. Urgent Mental Health Centre and peer led organisations providing services.
- We need a conversation about ratios to know what workforce mixes should look like.
- Make connections with other sectors i.e. housing, family support, low income support groups.
- LEx workforce includes project workers and team leaders. Voluntary workforce includes representatives and advisors.
- We need to work through contextual aspects of employment as currently industrial commitments and qualification requirements can exclude LEx candidates.

If we take short cuts

Infrastructure development will be mixed. Organisational/ personal risk when developing peer-based teams or increasing peer workforces will remain higher as well-known implementation issues will continue.

If we stay in the same place

While progress is occurring, service models will remain dominated by clinical perspectives into the future. Opportunities for growing the LEx workforce remain a mixed priority. Pathways remain project based. Continued low availability of peer support for consumers and carers.

SPOTLIGHT
examples on workforce leadership

The SA Lived Experience Workforce Project

The Lived Experience Workforce Project (LEWP) is overseen by the Mental Health Coalition of SA and funded by the OCP. The project utilises codesign practices to assist NGOs to recruit and grow the LEx workforce. This includes the production of standards and guidelines, information, online resources, and training opportunities for peer workers and managers who supervise lived experienced workers (LEWs). LEWP also assists in building capacity, recruitment and collaboration between NGOs and the government sectors, in promoting more pathways and opportunities for the LEx workforce. The LEx workforce toolkit has three versions of peer work implementation standards for specialist Aboriginal, LGBTIQ+ and CALD peers.

The Queensland Framework for the Development of the Mental Health Lived Experience Workforce

This framework provides detailed guidelines on the definition and understanding of designated peer roles, including senior and management roles. It also outlines strategies and best practice examples on organisational commitment, workplace culture, diversity, human resources policy and professional development and training.

Forthcoming National Development Guidelines for the Lived Experience Workforce

The National Mental Health Commission has funded a significant project in developing guidelines for the LEx workforce. These plan to be released in the second half of 2021.

Alternatives to Suicide (Alt2Sui) groups

Alt2Sui is a community based, peer facilitated approach offering mutual learning and support for people living with suicide related distress and is based on principles of validation, curiosity, and community. It aims to support people to find meaning and connection. It does not use a risk based paradigm. 'Discharged' groups, based in Western Australia, provide an example of how Alt2Sui groups are running in Australia.

Brook RED – consumer run organisation

Brook RED, a peer governed and managed organisation, has operated in Brisbane's South for 20 years. Its programs are flexible, responsive and recovery based and include one on one support, groups, a residential recovery service, a LBGTIQA+ group (Belong), a phone support service and NDIS services.

ECLIPSE Co-facilitated groups

Lifeline operates a co-facilitated support group program for people who have survived a suicide attempt. Group discussions and sharing are guided by peer support and mental health workers.

Hearing Voices groups

Hearing voices groups are peer led and facilitated self help groups which offer safe and supportive conversations for people who hear voices. The groups aim to help members share coping strategies and develop a positive sense of self.

9. Vision of a transformed mental health ecosystem

Most of the focus on LEx leadership and systems change has been about process outcomes. All of this work is about preparing services and programs which are coproduced and hope to change the experience of people seeking or needing help for mental health issues. As the last part of the Roadmap, it is important to describe the bigger picture of outcomes as related to recovery, citizenship and LEx, and the role of helpers. We know from literature that services which are coproduced or which have significant peer support services alongside clinical care have positive outcomes for consumer reported hope, empowerment, social networks (White et al. 2020) and quality of life (Bellamy et al. 2017). The ALEL Project therefore ends this Roadmap with a collective vision for the future.

Our Vision

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

Through taking action together a more holistic approach will guide change, and ensure that our language, power and mindsets, shift beyond biomedical and 'illness' dominated narratives. Upholding rights, giving control to people to determine their own lives and authentic co-design are essential foundations of the changes we seek. Services where people are valued, compassionate care is standard and accountability exists, offer people seeking support a better experience of care and better outcomes for their lives. Systems are strengthened when discrimination and tokenism are minimised and where peoples' dignity is prioritised.

Leadership across the system, including by and with people with LEx, is core to this vision being realised and is of itself a key driver of the broader systems change that the mental health and social services sector require.

10. Glossary and frequently used terms

ALEL – Activating Lived Experience Leadership project

LELAN – Lived Experience Leadership & Advocacy Network

LEx – lived experience. All aspects of the ALEL project is informed by the following definition of lived experience. Experience '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' (Byrne & Wykes 2020, p. 243).

Lived experience leadership – We approach this work with an understanding that mental health lived experience leadership is where people stand up and speak up for the recognition and valuing of lived experience and advancing the movement. This includes informal and formal activity which promote the values and goals of lived experience as relating to empowerment, peer services, social justice and citizenship. Leaders speak up to influence community awareness, organisational culture, policy and politics; leaders create space, pathways and inclusion with others; leaders prompt and support change

LHN – Local health network

MHSPRE – Mental Health and Suicide Prevention Research and Education Group

NGO – Non-government organisation

PAR – Participatory Action Research

PAG – Project Advisory Group

SA – South Australia

UniSA – University of South Australia

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12. Spotlight organisations, groups and resources

Following is a list of organisations, programs, groups and learning resources that were identified across the spotlights in the Roadmap. These titles contain URL links.

Aboriginal and Torres Strait Islander Lived Experience Centre

Aboriginal Health Council of SA (AHCSA)

Aboriginal Workforce Framework 2017-2022 (SA Health)

Batyr

Bfriend

Being - Mental Health Consumers - leadership training program

BPD Co

Brisbane South PHN co-designing the service model

Brisbane South PHN Commissioning

Brook RED

Co-design: doing it in the real world with authenticity

Co-production: putting principles into practice in mental health contexts

Consumer perspective supervision

Discharged (Alt2Sui) groups

Doors to Wellbeing

ECLIPSE Co-facilitated groups

Engaging with Aboriginal people (SA Health)

Hearing Voices groups

Information service – Adelaide LGBTIQ+ Events (Bfriend)

Lived experience transformational leadership academy (Yale Program of Recovery)

National consumer supports technical assistance grants program (SAMHSA)

National strategic framework for Aboriginal and Torres Strait Islander peoples' mental health and social and emotional wellbeing

National Training and Technical Assistance Centres

Nottingham Recovery College

NSW Lived Experience Framework

PEACE Multicultural Services

PENTAC

Rapid Enterprise Development (RED)

SA LEWP Toolkit

SA Lived Experience Workforce Project

SA Urgent Mental Health Centre: Philosophy of Care

Sanctuary

South Australian action plan for people living with borderline personality disorder (BPD)

South Australian Rainbow Advocacy Alliance (SARAA)

Substance Abuse and Mental Health Services Administration

The Gayaa Dhuwi (Proud Spirit) Declaration

The Healing Foundation

The Lived Experience Development Governance and Education (LEDGE) Project

The Mental Health Lived Experience Engagement Network (MHLEEN)

The Queensland Framework for the Development of the Mental Health Lived Experience Workforce

The Strong and Capable Cooperative

West Virginia Leadership Academy

Whyalla Ripples

Youth Affairs Council of SA

YouthMove peer centre