



Activating Lived Experience Leadership: Summary report on focus group research with lived experience leaders

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ALEL: Summary report on focus group research with lived experience leaders.

Overview

Purpose	To work with lived experience (LEx) leaders to identify how LEx leadership can be better recognised, valued and used across the mental health ecosystem in South Australia.
Key questions	<ul style="list-style-type: none">• How is LEx defined and understood in the South Australian LEx movement?• What strategies will help LEx to be valued and embedded across our systems?• How do we strengthen pathways for leadership?• How is LEx leadership linked to personal recovery?
Methods	The research used a participatory action research (PAR) approach. Stage 1 consisted of focus group discussions, held online due to COVID-19. An online forum was also used to share and develop early themes and findings with participants. Further follow-up online focus groups were then undertaken to reflect on and refine the findings.
Participants	Participants consisted of 31 LEx leaders. These included peer support workers, advocates, educators, group leaders and suicide prevention leaders. Participants included consumers and carers, and members of LGBTIQ+, CALD, Aboriginal, rural and urban communities.

Key findings

Defining Leadership: the central actions, qualities and skills of LEx leadership are mostly understood and recognised, yet many participants are not fully recognised by their organisations as leaders. Some participants also do not readily see themselves as leaders. Actions and skills include, standing up and speaking out, creating space, having LEx perspective/lens, reducing power imbalances, having authenticity, passion, empathy and connection, and working on the big picture. It was evident through the discussions that a clear model of LEx leadership is needed.

Links with recovery: LEx leadership is rewarding and connected with a deep sense of purpose and accountability to recovery practice, and to the peer movement. While positive about their work and involvement, leaders are exposed to stresses, risks and conflicts in driving change and being recognised as change agents within organisations and communities.

Networks and pathways: Participants indicated that the pathways for learning about the LEx workforce or systems advocacy, are underdeveloped nor easily accessible. Pathways to support between leaders are also lacking, and for some peers, supervision and mentoring are not available. Training pathways for peer support work are the most developed yet limiting for people outside of currently being employed in a peer work role. More opportunities for LEx promotion and communication are required.

Systems level actions: Multiple actions for structural, relational and cultural change were identified, including the need to reform models of care, increase the scale of LEx leadership positions and challenge stigmatised narratives of mental health. Further actions called for improved policy commitment and funding, better sector recognition and leadership, a coordinating LE leadership body, and promoting a culture of solidarity and leadership.

Introduction

This report focuses on the project's PAR¹ work with experienced and emerging LEx leaders in South Australia. The aim was to undertake focus group research with a diverse group of LEx leaders, seeking discussion and exploration of the four research questions of the project. There was a focus on exploring experience and perspectives of leadership and to identify key aspects where systems could change to better recognise, embed and use LEx leadership. Two other significant research activities 1) interviews with sector leaders, and 2) an online survey for LEx leaders, also addressed the research questions.

Our questions.

Specific focus group questions were designed by our Project Advisory Group (PAG) and the research team. These centred on:

- Becoming active or involved in LEx activity.
- Views of LEx leadership, including values, qualities and skills.
- Challenges and barriers to achieving change, or having work recognised.
- How personal recovery is linked to leadership activity.
- What change is required for LEx leadership to thrive and have impact.
- What are preferred networks and pathways for supporting LEx leaders.
- What are key learning topics and delivery methods.

Recruitment and participants

All research processes were approved by the University of South Australia Human Research Ethics Committee. The recruitment strategy was designed to invite a diverse group of LEx leaders to the project. This included people active in different roles and capacities, across distinct areas of the mental health sector and active in community initiatives, including peer support, mentors, project officers, community educators and speakers, advocates and advisors. The project also invited participants from various identity groups and networks, in both metropolitan and rural South Australia. People identifying as consumers, carers or having both identities participated. There was space in our definition of LEx to include diverse aspects of identity and membership. Most participants in the research spoke from the consumer perspective.

Recruiting for the research occurred by advertisement through various information networks. These included e news networks and social media accounts of the Lived Experience Advocacy and Leadership Network, Mental Health Coalition of South Australia, the South Australian Mental Health Lived Experience Register, University of South Australia and other specific community networks. A purposive snowballing approach was used, meaning participants and PAG members were able to promote interest among people through networks and memberships. 31 participants took part in seven first round focus groups. Six primarily identified as carers and 25 people identified as acting from personal experience of mental health challenges.

Methods

Our online focus groups were 90 minutes long and held using the Zoom platform. Discussions were facilitated by project leads, who are both identified LEx leaders. The groups operated in the context of shared peer values. All groups were audio recorded and transcribed. Each group ended with a summary identifying key aspects of discussion and standout themes.

We used a thematic analysis approach to identify both significant and prevalent themes across the discussions. This enabled the research team to thematically analyse participants statements and conversation, and coding these using a qualitative software called NVivo. This involved identifying and labelling key meanings and gradually sorting and collating significant statements. With the wide range of questions discussed, the number of codes identified were extensive.

People working primarily from consumer and carer perspectives participated in mixed groups. In this way the project worked to produce a generalised analysis on LEx leadership, pathways and systems actions, that would be inclusive yet reflect content meaningful to both perspectives. As the focus was on leadership, advocacy action and systems, a broad focus was possible while we were mindful of the differences in perspective with each participants contribution. Some question areas e.g., personal recovery and leadership, were discussed and grounded in consumer perspective.

Each transcript was coded as groups were completed and after the first round of focus groups, an anonymous online forum was created to share themes and understandings generated across all of the first-round groups. The main themes were posted, inviting discussion and reflection, and focusing on what was most important to develop in terms of change. We used mind maps as a way to display themes relating to each question, with these also including subthemes. The online forum had a modest amount of engagement and discussion.

A second round of focus groups was conducted to continue discussions with a focus on networks, support and skills development. Four groups were held with 15 people participating. As a feature of PAR, emerging findings of the research were shared with the wider networks and audiences of the project, including Summit³ participants, and other sector and LEx leaders and invited responses. A systems change approach was encouraged by focusing on structural, relational and cultural features of human service systems⁴. PAG members also played a role in analysing themes of the data, in relation to the research questions, social change and problem solving. These are important processes in PAR⁵.

Key findings and themes

How would you define LEx leadership? What are key qualities and skills?

LEx leadership in focus group discussions was understood as standing up and speaking out, and the process of leading change. There was also an understanding that leadership activity occurs in the context of a collective social movement for change. The analysis noted that leaders do not always recognise their actions as being leadership, or that activity for change is recognised as leadership by the organisations they are active in. The key actions that leaders do were identified across groups.

Leaders:

- Create and hold space for others.
- Promote empowering spaces and culture.



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- Use LEx lens and offer a distinct consumer, carer or personal perspective.
- Inspire vision for change.
- Critique injustice and name issues.
- Build networks, mobilise and act strategically.
- Offer consumer centred responses.
- Reduce power imbalances.
- Are an ally for other justice based movements.
- Educate others, including clinicians.

LEx Leaders often embody distinct qualities and skills. These were identified as:

- Having great empathy and the ability to connect well.
- Having hope, passion, persistence and determination.
- Being authentic, honest and having integrity in peer values.
- Expressing mutuality and equality.
- Having well developed communication skills and voice.
- Having respect, reputation and influence.
- Understanding the uniqueness and diversity of LEx.
- Using lessons of LEx and LEx work.
- Expressing authentic recovery.
- Working at big picture, systems level.
- Working across personal/public spaces.
- Reflecting on power dynamics and decision making.

*...the lived experience leader isn't just able to purposefully draw from their own, but makes way for others to also be able to do that as well, so brings others along with them...it's about how I can use that to help others to feel comfortable and find ways to be able to use theirs...to be able to provide a space in that collective lived experience to create that change or to influence.
(LEx leader).*

It has a whole another lens that we didn't even know that we didn't have and now we can see things in a whole different way and it's just a whole another - I'm not disregarding the accumulated knowledge that people can get from doing degrees and from studying, but the lens that you can get from living it, is a whole another way of looking at how to support these people. (LEx leader)

I think a good leader is aware of this and can actually break down those barriers to support individuals, to build their narrative, to learn and to find community and meaning or whatever's important to them. (LEx leader)

Giving back, being grateful, making a difference, and having meaning, moving beyond shame and guilt and embarrassment – emancipation! And it makes me think of holding space between us for hope. (LEx leader)

What is important in communication? What key messages do you use?

We asked these questions about communication to help identify the approaches and techniques that leaders use for messaging and influence. The analysis found that there was significant diversity in people's views on communication. The key ideas were that:

- It's important to have a LEx lens when shaping your communication, and forming key messages.
- Personalised, and informal forms of communication are important for building relationships with allies.
- Setting boundaries on personal disclosure is a required feature of LEx work.
- The language of LEx does not exist in many cultural groups and communities and needs to be explained and interpreted within these contexts.

Key messages

- On recovery: there is hope; change is possible; you are not alone; we are not broken or defective; LEx makes me a better person; self-care; we all have unique journeys.
- On LEx: we have valuable knowledge, which is shared practical and realistic, and represents deep learning.
- On being a part of the sector: We deserve to be here; stigma needs to be challenged; LEx is an essential part of the system.

I try to get across is that I'm not that broken or defective, I just experience things differently than somebody else might and, for whatever reason, history has called it mental illness and perhaps that might change at some time down the track...isn't stigmatising, that isn't focused on deficits but is looking at the whole person and looking at the experiencing, trying to humanise – I feel like lived experience is very much about humanising. (LEx leader)

How is personal recovery linked to LEx leadership activity?

Focus group discussions identified a number of themes on how using LEx and leading change is connected with personal recovery. The discussions highlighted the rewarding aspects of leadership activity while also identifying key challenges and exposure to risks. The most prevalent and meaningful themes were:

- LEx work gives me purpose – it's the right place for me.
- Talking recovery increases my accountability to my own recovery – have to walk the talk.
- I get exposed to stresses, conflicts and risks.
- I have experienced lateral violence in the lived experience community.
- There are pressures – workloads and worry about roles.
- Giving to others furthers my recovery.
- LEx activity promotes acceptance, self-respect, dignity.
- Opportunities to learn new skills.

As soon as I got my peer work role, I rarely took a sick day and I was always there and I wasn't getting fired and I was like, I just had to do something that was meaningful for me. I'm meant to be now and I really love it. (LEx leader)

...the accountability of being in a lived experience role because you know that others look to you for inspiration or direction or how is this person doing this and being so open about having lived experience and yet they're able to do this, this and this, and I think that that keeps me accountable. (LEx leader)

I think both, because on the one hand obviously working in the roles that we do can be exhausting and can be triggering. So, we really need to practice those skills that we have, to keep ourselves well. On the one hand, it does take a lot of energy. (LEx leader)

Pathways: How did you become involved in LEx work?

There was a wide range of responses, yet the following patterns were evident.

- I got involved in public speaking roles e.g., in suicide prevention.
- I came across a peer work role position and applied.
- I got involved in advocacy and committee work, seeing the work of others.
- I just discovered this passion for LEx work.
- I decided to fight for dignity, justice and rights.
- I realised my LEx was valuable for others.
- I came across this area by accident.
- I started mentoring others.

These themes indicate that people find various pathways which are well known in organised LEx activity, including speaking roles, advocacy and peer work^{7,8}. However it was evident that these opportunities are not well known in the broader community. Many people reported long mental health journeys before becoming aware of these opportunities or the concept of LEx as valuable.

I started studying psychology through my own lived experience and randomly applied for a peer specialist job with (name of service). I didn't even know what a peer worker was when I applied, I just thought, this sounds cool. (LEx leader)

I became involved by my own personal experiences bringing me to work as a peer worker in my recovery journey and the growth and the living that and sharing these experiences with other people puts you in a position and a situation where you naturally become a leader and an advocate for yourself and for others. (LEx leader)

And I just discovered this passion, and for me the feeling of realising that everything I'd been through, that I thought I was different and lacking and broken and all these things, it was actually really valuable because it could help other people. (LEx leader)

What are preferred networks and pathways for supporting LEx leaders?

Four follow-up focus group discussions featured rich detail on preferred networks and supports for connecting and developing LEx in South Australia. There were six areas of network development identified:

- Support and learn from each other by providing/receiving mentoring, sharing resources and skill sets, and recognising different levels of support (formal and informal).

- Build networks organically, building links with established groups, working beyond funding streams, providing allyship.
- Promote improved pathways for LEx peer supervision, including appropriate models and expectations, improved access and management support.
- More coordinated information networks, with a focus on facilitating leadership opportunities, training and holding events across diverse LEx groups.
- Strengthen learning pathways across both peer support and systems advocacy work, lifting leadership capability and promoting opportunities for those between jobs or volunteers.
- Considering different models of learning on leadership, e.g., mentoring or coaching. Recognise different learning styles and requirements and advantages of each model.

Strong sense of community. We need bigger, broader networks that are more accessible...because we've talked a lot about the isolating nature of some roles, we need a bigger community that's more accessible to all and who is constantly working together to define that collective voice more often. (LEx leader)

...from my perspective, particularly now actually through the pandemic, it's really important and part of leadership is to read the times, the signs of the times and effectively, but I think there's a role for the lived experience community to be more a collective force, a form of solidarity. (LEx leader)

...as a community it would be great, as well as having the mentoring and supervision, that we are able to support one another and say, 'Look, I'm at a wits end with this particular thing,' or, 'it isn't my strength area. Is anybody interested or is somebody out there that can do this and what can I do to help you in your role?' (LEx leader)

What are important learning topics and delivery methods?

One of the roles of the ALEL project is to discover areas of learning regarding LEx leadership action. The discussions identified four themes about topics and two ways of organising or delivering training.

Learning topics:

- Communication skills such as public speaking, sharing stories with purpose, boundary setting, when to challenge, assertiveness and confidence in speaking.
- Advocacy principles and skills, including presentation of issues and being influential, how policy and systems work, managing conflict and change, consultation skills, allyship and building networks.
- Leadership in organisations, focusing on supervision and workforce management, project management, managing up, team self-care, debriefing and supporting team interests.
- Self-care and supporting others, including responding to stigma, saying no/setting boundaries, working through conflict with peers and allies, working with frustration and disappointment and general mental health literacy.

Delivery options:

- Preferred learning methods include a mix of online and face-to-face sessions, using a skill sharing approach, with follow up learning support and respecting diverse learning styles.
- Easy language is essential.
- Online training offers ability to record sessions and have varying lengths, such as 15/30/120-minute sessions.
- Training should target specific topics and audiences. Encourage learning at own pace.
- Training should be widely promoted (across South Australia) using calendar of events.

What are the challenges and barriers to achieving change, or having work recognised?

There were a wide range of identified challenges and barriers throughout discussions, with many of these also consistent with literature. These centred on expectations⁹, organisational recognition, relationships with team members, managers¹⁰ and communities, and employment environments^{10,11}. The most commonly expressed barriers and challenges are grouped into themes.

- Exposed to stigma, deficit-based stereotypes and paternalism on mental health. People also exposed to other discriminatory attitudes: ableism, homophobia, transphobia.
- Lack of recognition and support from some clinicians, managers, allies and organisations, and feelings of isolation.
- Issues in 'being out' in terms of mental health, but also other personal aspects of identity such as sexuality, gender and ability. Personal stories impacting other family, issues in small communities. The need to stand tall in your LEx.
- Lack of supervision and mentoring for leadership within employed roles.
- Frustration and burnout from volunteering, token responses; managing self-care and staying motivated.
- Being seen as a leader, undervaluing self, lack of suitable leadership models.
- Role tensions, time barriers and managing boundaries.
- Pressure from being the 'go to' person; to be the expert or sole consumer representative.
- Recognising intersectionality across LEx, and whole identity within LEx roles.
- Inner dilemmas, staying true to peer values, dealing with imposter syndrome.
- Lack of community understanding, or awareness of LEx or recovery concepts, challenges in working across community languages and cultural expectations.
- Conflict, lateral or vertical violence in LEx communities.
- Dilemmas in pushing for change, managing up, challenging others.

There is also the challenge of pressure to be the expert - you're the 'go to person' for the area you have lived experience in - sometimes you're the LGBTIQ+ expert, sometimes it's disability issues that need attention, sometimes mental health...organisations do put pressure on the one lived experience role to do it all. (LEx leader)

I step up when no one else will. I think it's this willingness to get on with it and do the work when other people are either too busy or not interested in doing it that makes me stand out. It can be incredibly exhausting though as I feel obligated to fill gaps when no one else is, and I've had to force myself to step back from a few roles that I really wanted to be involved in so that I didn't burn out. (LEx leader)

...isolation and, especially, I think, living in South Australia, there's just not that many of us, and being the only one in my local [health service] and the only one in my role... that can just be a bit exhausting sometimes, then you're always wondering is this tokenistic, is this valuable? (LEx leader)

What change is required for LEx leadership to thrive and have impact?

This question created discussion about the preferred changes that could occur on a systems levels for better recognition, valuing and uptake of LEx leadership. The suggested actions spanned different aspects of systems including cultural change, leader behaviours, creating more opportunities and policy and funding activity. Preferred changes include:

- Working to obliterate stigma and tokenism.
- Reforming models of care to include significant LEx workforce.
- More LEx leadership positions in organisations.
- Improved policy commitment and funding opportunities.
- Better frameworks for generating shared understanding and options.
- Better quality sector leadership and commitment for valuing LEx leadership.
- The resourcing and development of peak bodies for peer work and systems advocacy.
- Better solidarity and allyship across LEx groups.
- Improved pathways to LEx leadership.

Leadership to thrive we need reformed models of care, funding communities of lived experience people, supporting each other to foster healing cultures and reforming the way that Mental Health services are provided for people within the community and in times of distress. Communities that embrace authentic lived experience lead recovery frameworks, reclaiming agency, living and educating themselves and others of what may be possible. (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)

I think having a peak body would really help to formalise...[and] help other professions to see lived experience as a valid profession. (LEx leader)

Reflections and conclusions

Leadership models and recognition

Discussions on LEx leadership and also the challenges and barriers indicated the complexity of issues faced by many people seeking change in the sector. Being strategic in responding to stigma occurred in different contexts, from working in community education to public mental health services. Many participants reported the constant inner work of assessing expectations and boundaries that come from being out, and also in shaping relationships with colleagues and employers. Many participants reported that their change agent roles, in terms of recovery agendas, or challenging stigma, discrimination or injustice, were not clearly understood by organisations. This complicated their work and expression of leadership.

It is clear that LEx leadership is an emerging concept and practice, in the way it is understood and expressed within LEx networks and organisational contexts¹². The findings indicate that the overall attributes and roles of LEx leaders are evident¹³ when discussed, but often people are not acknowledged as leaders, or that it is seen as a part of established roles (e.g., peer support worker, consumer representative, community educators, or initiators). Some participants also did not consider themselves as leaders, despite their change agent activity. Leadership is not commonly understood by the wider mental health system as a key feature of organised consumer and carer activity. However, it is required to guide and coordinate development according to the values of the movement¹⁴.

Many of the themes generated on the experiences of leadership and advocacy practice are meaningful to both consumer and carer interests, while also reflecting differences in perspective. Stigma, in terms of mental illness and suicide was raised from both points of view, in terms of the effects of being out, boundaries on the use of personal/family stories, and experiences of discrimination. Allyship was another theme that was commonly discussed, as well as the challenges of being undervalued in organisational contexts, and at times, thwarted recognition of speaking from lived experience. There are however, key directions and findings that are centred in consumer perspective and these relate to the intrinsic relationship between personal LEx, marginalisation, service use, impacts on identity, the recovery journey, and how leadership emerges from this context. We encourage readers to reflect on the context and journey of LEx leadership from each perspective.

Networks and pathways

Findings from the areas of becoming involved, and preferred networks, indicate that pathways for supporting LEx leadership in South Australia remain underdeveloped. This is particularly so for becoming involved in advocacy activities, and in the links across LEx groups in mental health and wider networks i.e. between suicide prevention networks, specific consumer advisory groups, and diverse advocacy groups in the LGBTIQ+, or disability spaces. Pathways exist to become involved in peer support work, but these are not widely promoted or visible to the general mental health community. There are also limited places available for the Cert IV in peer support work by local providers. The research team observed that pathways are often minimal and defined by services rather than by the LEx community, where they can be aligned with values and approaches of the movement. Participants identify a rich range of topics for learning and ways to strengthen network development.

Recovery and leadership

Findings across the focus groups indicate that many participants see LEx leadership in terms of becoming active in LEx work as well as being connected to their recovery. The general theme was that LEx leadership is highly rewarding and meaningful in terms of personal recovery, while also stressful and tiring at times. Managing energy, boundaries and self-care, as well as seeking to shift organisational or power dynamics, was a balancing act for many people. Challenging stigma, promoting recovery or suicide prevention, and working with dominant clinical perspectives was a part of shaping these dynamics. Maintaining a LEx lens and staying true to peer values, and projecting accountability were other features to manage for many participants.

Action for systems change

Actions were identified for supporting changes in policy development, organisations and culture. For policy, participants identified the importance of strengthening commitment to LEx leadership via peer support workforces, advocacy roles and community initiatives. Commissioning and funding specific LEx initiatives on both systems and organisational levels was seen as a way of generating presence and opportunities. This complemented the theme of reforming models of care so that LEx workforces are more available to the public. Organisational level actions focused on encouraging executive leaders to promote opportunities for LEx in terms of workforce growth, team leader or manager positions and in decision making. This included creating dedicated budgets. Actions to shape 'system culture' included those challenging stigma and othering, developing frameworks of shared understanding and definitions of LEx leadership and involvement, and fostering a culture of allyship. Participants highlighted the need for collective LEx leadership and a guiding organisation, noting a lack of ongoing funding for peak body activities at state and national levels.

The research team noted that examples of some of these actions are evident in South Australia. There is a gradual growth of the peer support workforce, and some examples of LEx service commissioning, alongside other organisations development of LEx involvement frameworks. However, the research team observed that there is a clear gap of understanding and action in terms of these strategies being articulated and invested in at the systems level, so that they are clearly present to enhance the work of LEx leaders locally.

This report has summarised the processes and findings of our focus group research with LEx leaders. As part of a broader PAR project, the findings have been produced via thematic analysis and ongoing reflection with participants and the broader audience of the project. Knowledge production in PAR is about identifying challenges and problem-solving actions which are both meaningful and useful for the people who live and work with these challenges⁵. We consider that the findings are a rich and credible reflection of the collective views and perspectives of LEx leaders participating in the study.

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