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Activating Lived Experience Leadership: Summary report on research interviews with sector and service leaders

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ALEL: Summary report on research interviews with sector and service leaders.

Summary

Purpose — To work with sector and service leaders to identify how lived experience (LEx) leadership can be better recognised, valued and used across the mental health ecosystem in South Australia.

Key questions

- How is LEx defined and occurring across mental health services and systems in South Australia?
- What strategies will help LEx to be valued and embedded across our systems?
- How do we strengthen pathways for leadership?

Methods — The research followed a participatory action research (PAR)[1] approach. Stage 2 consisted of individual interviews with sector and service leaders within a PAR approach. Due to COVID-19 interviews were facilitated through a video platform or via telephone. Transcribed interviews were analysed to identify central themes of understanding and practice, and then shared more broadly across project participants for further development.

Participants — Participants consisted of 14 sector and service leaders. This included leaders of NGOs, government programs and public mental health services. Some participants worked in rural contexts. Several identified as having LEx, as a consumer and as carers.

Key findings

Leadership and recognition

The study found that LEx leadership is described by sector leaders in terms of advocacy work, driving community initiatives and learning, challenging stigma, creating safe spaces and stories. The qualities of taking initiative, having authenticity, courage, empathy and passion were listed, as were the skills of using LEx perspective and working to create change across diverse settings.

Participants indicated general patterns where LEx leadership is active in terms of organisational planning and involvement, within community initiatives, in some policy forums and in the LEx workforce. Facilitating the involvement of diverse LEx voices is an ongoing challenge. Participants report that a meaningful presence of LEx leaders on boards and other governance bodies is not in place across the sector, and that dedicated budget lines, KPIs and other infrastructure to drive LEx leadership is limited or absent. Leaders report uncertainty in terms of how LEx leadership is recognised and achieved in terms of designated roles versus non designated roles, and the right mix of positions within organisations.

Systems level actions:

Six themes regarding system actions were identified for improving the recognition, valuing and use of LEx leadership: 1) improving policy and organisational infrastructure; 2) creating shared understandings and expectations on LEx leadership in mental health service culture; 3) better executive level leadership for recognition, resource allocation, trust and accountability; 4) promoting more LEx leadership

positions in higher places of influence; 5) Service reform which includes substantive LEx workforces and peer based approaches; and 6) the development of pathways and supports for growing and nurturing LEx leadership, including peer led mentoring, debriefing and supervision.

The actions reflect a systems change approach to generating change on structural, relational and cultural levels.

Introduction

This report focuses on the project's PAR work with sector leaders and their involvement with experienced and emerging LEx leaders in South Australia. The aim was to undertake interviews with sector leaders, exploring their experiences and perspectives and identifying where systems could change to better recognise, embedded and enable LEx leadership.

Our questions.

Our interview questions were designed by our Project Advisory Group (PAG) and the research team. These were:

- Is LEx leadership active in your organisation? How is it occurring or not occurring?
- What about LEx leadership has worked well within your organisation?
- What are barriers and challenges for LEx leadership? And supports?
- How do you define LEx leadership and influence and encourage diversity of voices?
- How does LEx leadership contribute to mental health reform and service change?
- What are ideal ratios of LEx leaders in an organisation?
- What would enable LEx leadership to thrive and have impact?

Recruitment and participants

The project used a purposive sampling approach to invite NGO and government sector managers to participate in the study. Sector leaders who had knowledge of and were active in supporting LEx leadership within organisations and systems were invited to participate. Recruiting occurred by advertising through 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, University of South Australia and other specific community networks. A snowballing approach was used, meaning participants and PAG members were able to promote the study among other leaders in their networks. All research processes were approved by the University of South Australia Human Research Ethics Committee.

14 sector and service leaders took part in interviews with the research team. The leaders represented managers and executives of NGO and public mental health services, as well as leaders in suicide prevention agencies. Policy leaders also participated. People working in rural South Australia were a significant part of the sample group. Five leaders identified as having LEx as a person living with mental health challenges or as a carer.

Methods

The interviews were 45-60 minutes long and were conducted online using a video platform. All interviews were recorded and then transcribed. Interviews were conducted together by the project leads, who are both identified LEx leaders. The interview transcripts were sent to participants for checking for accuracy and then analysed to identify significant and prevalent themes and concepts across the discussions. NVivo software was used to identify key meanings and statements, and sorting these into categories and codes. Summaries of the many codes and ideas generated broader themes. The analysis was informed by a systems change approach, and focused on the structural, relational and cultural aspects of human service organisations and systems[2].

As a feature of the PAR approach[3], the emerging findings of the sector leader interviews were shared with the wider networks and audiences of the project including Summit[4] participants, and other sector and LEx leaders. Responses were invited. Themes generated from the interviews with sector leaders were compared with those from LEx leaders.

Key findings and themes

How is LEx leadership occurring?

Mixed views were generated on the scope and reach of LEx leadership activity within organisations and system areas. In terms of occurring, sector leaders most commonly reporting activity in:

- Organisational planning and consultation – via advisory groups and specific events.
- Community initiatives and projects – e.g. in suicide prevention and education networks.
- Workforce development – LEx leaders on recruitment panels and employing peer support workers.
- Clinical governance and safety and quality committees – in public mental health services.

> *They're very much on the advisory, maybe a little bit of co-design, but that tends to happen if there's money for projects, but definitely not positions per se. (Sector Leader)*

A significant theme in these discussions was the challenges of ensuring diverse voices are heard within organisational planning and consultation processes and how LEx leadership is achieved relating to Aboriginal, CALD and LGBTIQ+ communities. Within this, participants talked about barriers in low budget allocations, limited knowledge of strategies, lack of staff capacity, and challenges of geographical distances as impacting on the reach and inclusion of involvement practices. Leaders spoke on the positive impacts of LEx involvement for producing more relevant and solution focused service responses. Very positive LEx impacts on service reform are evident in some places, but *I think there's still a long, long way to go. I think that a lot of it is still quite tokenistic… (Sector Leader)*

How is it not occurring?

It was evident across the analysis, that LEx leadership is not occurring at the levels of management, board governance, or in terms of higher-level team leader roles.

> *Only recently. It hasn't really been a thing in my organisation. And only recently, have they started to acknowledge lived experience workers and understand what that term means and that sort of thing. (Sector Leader)*

It is also absent in many higher-level systems and policy forums.

> *I think that their lived experience leadership is more understood and integrated in other mental health specific NGOs. I didn't see an example of that around the [government department] table or various forums that I went to, which were many. I didn't see any difference. I saw 'we're the leadership – and we have a peer workforce down here'. (Sector Leader)*

Most sector leaders were unsure about how to frame or recognise the LEx of existing workforces, where it was acknowledged that many organisational workforces have high levels of LEx, but which are not formally recognised.

> *We don't have designated leadership positions within South Australia but certainly I myself have a lived experience and I suspect we've got several other people in leadership roles that do, but they're not designated or certainly not in their title or potentially not even known to other people. (Sector Leader)*

Many leaders were unsure about ideal levels of designated LEx leadership within a workforce. A quota of 50 per cent was suggested. Many participants did not have a clear opinion on quotas, although another participant suggested that organisations should be 100 per cent LEx.

How do you define LEx leadership?

All sector leaders were able to relate to the actions, qualities and skills of LEx leaders involved in their organisations and communities. When asked to define these, they reported LEx leaders as:

- Having unique voice and perspective, creating space and safe conversations for others, identifying and articulating solutions, and having influence.
- Being able to stand up and take initiative, building effective relationships, providing community messages and effective storytelling, setting challenges and creating effective responses.
- Being inspirational, passionate and empathetic, and having charisma, authentic presence, and courage.
- Working across informal and formal contexts, finding own level of involvement, working inside and outside of organisations and systems.

I guess there are two of those types of leadership and my experience is, the people who are doing the best at it are the people who have the charismatic leadership style. So, the people who have drive and passion that other people follow them because of that charismatic style. (Sector Leader)

But I think what it does is the compassion and empathy and understanding that you have from your own lived experience shines through in your work. (Sector Leader)

...we have a really strong lived experience leader who is from an LGBTIQ+ lived experience, and so (this person) actually set up some initiatives around LGBTIQ+ in a country area, and a (group) centre, and all of these initiatives for those people of that cohort who we know are at high risk, but [they] have done that from [their] own lived experience perspective because [they've] lived it. (Sector Leader)

What are barriers and challenges for LEx leadership? And supports?

Our analysis identified five broad themes relating to challenges and barriers. These also were meaningful in discussing preferred forms of support. The discussions were focused on barriers and challenges that were evident at both organisational and systems levels. These were:

- Lack of dedicated supports and infrastructure including financial and people resources for required 'larger scale' involvement, and skills for coproduction practice.

  I think also you need to work with the communities that are engaging effectively with the people that you're seeking to involve. So, I think that often within government agencies we try to have a single Aboriginal clinician or a single CALD clinician, whatever that means, and that tends to be ticked off as that particular element achieved. And no matter how fantastic those people are, and often they are really super fantastic, they're unable to represent the diversity of that community and the ways in which practice should occur. (Sector Leader)

- Lack of supports and pathways including challenges of enabling involvement of diverse groups and voices across identity and geographic distance and supports which enhance leadership.

  I do try to include that as a comment whenever people talk about a lived-experience program or a lived-experience consultation, is that I want to hear from the people who don't want to be heard or they don't feel they can be heard and, of course, it's an unknown [voice]. (Sector Leader)

- LEx leadership is not understood, valued or possible including a lack of recognition, understanding and action due to complexity of designated/non designated roles, the burn and churn of systems, and shifting priorities.

  I think part of it lies in having full recognition of the expertise and the benefits of it. I think sometimes the decisions that are made at a systemic level are not always necessarily about people, it's about money and it's about other things and I think that gets in the way. I think sometimes organisations are so busy trying to adjust with some of the changes that happen just

to try and stay afloat and trying and keep people they are supporting as best as possible but sometimes their focus shifts as well. I think there are those issues. (Sector Leader)

- Relationships and power dynamics relating to resistance to LEx leader's presence and dominance of clinical power and perspective within a culture of risk and control

  I think it's really tough for them to give up power. I think it's really tough to sit in an unpredictable enough space to be able to enable a person who doesn't have doctor written before their name, either a PhD or a clinical one, to be able to have an influence. (Sector Leader)

- Stigma and stereotypes including barriers in communities, organisations and professional cultures where stigma stops people coming out or creates risks for doing so.

  I mean, I think there are some even within mental health, there are prejudices and there are biases and some of that is around what a person with lived experience diagnosis might be, you know, there are some diagnoses that, I guess, are confronting for people and they will have preconceptions about what that might be based on their own experiences and so you have to work through that. (Sector Leader)

What would enable LEx leadership to thrive and have impact?

This question was the last interview question and encouraged a significant diversity of exploration and perspective. Six main themes were generated to represent the range of suggestions and thinking offered. Overall sector leaders felt that the following needed to be actioned:

- Create and promote LEx leadership pathways including improved internal and external pathways for debriefing, mentoring, supervision and coaching, and a culture of enabling, growing and nurturing leaders.

  But unless you give people some challenges and things they can achieve and some goals to help them do that, then you actually don't give them the authority to move on. You don't give them the ability to move on. So, I think some of it is just structure around leadership that you give them some work in structure, and support to achieve. And I think a whole lot of people will blossom fairly quickly. (Sector Leader)

- Improved executive leader actions focusing on better recognition, openness, support, trust and accountability for LEx leadership.

  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. So that I mean for me, there's those things. There's the trust and respect down in the ground and then there's the overall systems statement that this is…actually being pursued. (Sector Leader)

- Improved knowledge and infrastructure including LEx leadership and involvement strategies, leveraged resources across organisations, recognition in policy, standards, funding and KPIs.

  Definitely there is a sector responsibility. If we, like I say, 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, I guess, 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. (Sector Leader)

- Leaders in higher places of influence enabling improved LEx presence on boards and other governance bodies, recognising roles of systems advocacy, and creating more LEx team leader/management positions.

  Unless you have internal advocates, but it doesn't matter if it's just around lived experience of mental illness, unless you have those same sorts of voices, you're encouraging your organisations around gender diversity and sexuality. Unless you have those same sorts of voices in there around First Nations or about women's rights or those sorts of things, then it's really easy, as a middle-aged white bloke, to fall into that trap of just doing what middle-aged white blokes do because it's what we've done for the last 1000 or so years. So, I think that that formalised role of advocacy within an organisation is absolutely critical. (Sector Leader)

- Service reform with a focus on genuine coproduction, commissioning with LEx partners, recognising peer-based methods and increasing LEx workforce to reach critical mass.

  And a true partnership, you know, not just lip service and tokenism, just in a true partnership, where people are sitting around the table, they're validated, they're part of the team, they're part of a service. They're an essential core element of the team, service, whatever. (Sector Leader)

- Increasing shared understanding relating to clear expectations of LEx and designated roles, with meaningful goals and processes, and recognition in policy and standards.

  I think having designated roles for me assures that we have, like, direct in bringing the lived experience into the organisation. Also, it makes it, kind of clear. It makes it clear that there is an expectation that you will use the lived experience, so, we are clear and open in that as opposed to recruiting somebody that happened to have it and then we say it would be really good if you could use the lived experience and they say, I'm not comfortable with that. Whereas here, it's open. The expectations are known. Everyone is in agreeance with how we want that used or what we want to try and achieve as a result of that, so, that's open and that's clear and I think that's important to have and we work with that person. (Sector Leader)

Key points and conclusions

LEx leadership models and recognition

The study found that sector leaders have a significant understanding of the roles, qualities and benefits of LEx leadership. The descriptions offered aligned well with those in the literature in terms of the advocacy role, having influence, challenging stigma, creating safe spaces and storytelling[5,6]. While these definitions were apparent across public mental health and suicide prevention, an observation in the suicide prevention space was that LEx was leadership directed more towards community initiatives and education, and less focused on navigating organisational hierarchies and decision-making boundaries.

In terms of levels of activity and recognition, the study suggests that LEx is mainly occurring through community initiatives, organisational planning and service development, LEx workforce development and in some policy forums. Participants could clearly point to examples of good practice but indicated the scale and resourcing of activity was at low levels, compared to what was needed. A regular example was the low funded capacity of mental health services to engage in robust consumer and carer involvement, involving diverse identity groups and spanning geographical distances in country settings. As reported in other studies[7], LEx leadership does not have a significant presence in board rooms, and there isn't an infrastructure or clear set of expectations around achieving this.

Two other themes are important to highlight. The participants questioned how LEx leadership was best operationalised, noting the context of designated LEx roles and the high numbers of existing workforces and leaders with LEx who had not made known this information within the context of their current employment. This reflected the complexity and emerging nature of the field in that clear expectations and ethics in this area have yet to be established locally[8]. The other was that leaders felt that the bigger picture goals of LEx leadership or involvement were not clearly articulated. The aspiration of ratios of LEx roles compared to non-designated LEx roles reflected this and showed that these discussions need to occur at the systems level.

Actions for systems change

The focus on challenges and barriers, and the key themes expressed, show that development is required in terms of policy, practice, resourcing, and in relationships and culture. This was also reflected when talking with participants about systems change for LEx leadership to thrive and have impact.

Participants reported that improved policy and organisational infrastructure is required. This relates to capability of organisations and leaders to have pathways and supports in place for achieving more robust coproduction with consumer and carer involvement processes, and for growing and nurturing LEx leadership. This infrastructure extends to supporting LEx leaders as members of boards, other decision-making bodies and workforces[5]. Pathways and supports include well described processes[9] of debriefing, and peer led supervision and tailored mentoring.

A related action is in creating shared expectations and understandings on the value proposition of LEx leadership, and how this occurs in terms of workforce and systems advocacy. The further development of expectations (e.g., via strategic frameworks) on organisational and systems levels is required and should include reference to designated/non designated LEx positions[6].

Participants recognised that executive leadership is required to drive these areas of development, with this being important in recognition and valuing, allocation of resources, and building trust and accountability. Executive leadership is required to share power while reshaping culture, and helping organisations work effectively with both clinical and peer paradigms of mental health[10,11].

The up-scaling of LEx leadership was another theme of discussions. Increasing numbers of leaders is related to having the infrastructure, shared understanding, networks and supports in place. It is also related to service reform. This is about continuing to develop service responses which are relevant and meaningful to local consumers, families and communities, and which include substantive LEx workforces and peer support approaches.

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