



Activating Lived Experience Leadership: Report: online survey with lived experience leaders

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ALEL: Report on online survey research with LEx 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	
	 How is LEx leadership defined and understood in South Australia (SA) and other states/territories? What strategies will help LEx to be valued and embedded across our systems? How are pathways strengthened for leadership? How is LEx leadership linked to personal recovery?
Methods	An anonymous, text based online survey was designed to invite LEx leaders to share their views within a participatory action research (PAR) project. The seventeen-question survey was promoted in South Australia and other states and territories via LEx peak bodies and networks.
Participants	Invited participants were self-identified LEx leaders. These included peer support workers, advocates, educators, group leaders and suicide prevention leaders. Participants included consumers and carers, members of LGBTIQ+, CALD, Aboriginal, rural, and urban communities. 48 meaningful responses were received.
Key Charles	

Key findings

Defining Leadership:

Participants see the actions, skills and qualities of LEx leadership as being centred in social advocacy, mobilising and leading change. Actions also include sharing experience, supporting and empowering others, using LEx lens, creating safe spaces, challenging stigma and educating others. Effective leaders express the qualities of offering hope, inspiration and empathy, and are passionate and influential. LEx leadership needs to reflect the values of the consumer movement and an analysis of power and influence.

Links with recovery:

LEx leadership is rewarding and meaningful in enabling people to give back, share and grow within leadership. Taking on leadership is positive if the rights supports are in place, and these help leaders negotiate multiple stresses associated with working in, or across advocacy and peer work contexts in mental health organisations and communities.

Networks and pathways:

Diverse pathways exist for peers to engage with roles and opportunities for leadership. Participants see the leadership requirements of systems advocacy as distinct to peer support or service delivery but highlight that both should be grounded in common LEx values and purpose. Both formal training and informal pathways of mentoring, supervision and support are required across LEx roles and leadership activity.

Systems level actions:

Five main action areas were identified including 1) ensuring LEx voices at all levels of influence; 2)

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improving education and shared understanding about the LEx movement; 3) enhancing LEx leadership pathways; 4) improved sector leadership, and 5) service reform and increasing the peer workforce.

Introduction

As part of the Activating LEx Leadership Project (ALEL), an anonymous online survey was made available to LEx leaders to hear views and perspectives on the questions of the project. The survey was promoted to LEx organisations and networks on a national basis to receive broader input than South Australia alone, and to enable another method of participation for LEx leaders. It was also done to provide an additional source of data, to complement focus group research with LEx leaders and interviews with sector and service leaders. This was part of a data collection and learning strategy within a participatory action research approach (PAR)¹. The overall aim of the ALEL project is to identify and encourage action so that our mental health system is better able to recognise, embed and utilise LEx leadership.

Survey background and questions

The questions of the survey centred on defining LEx leadership, exploring links between leadership and personal recovery, identifying organisational and systems actions to support leadership, and how pathways, learning and supports for advocacy and peer support work can be improved. The survey questions were based on the those used across the project, with the online survey tested and feedback provided by the Project Advisory Group members.

Methods and data collection

This research was approved by the University of South Australia's Human Research Ethics Committee in January 2020.

The survey was hosted on SurveyMonkey and all responses were anonymous. The survey included six descriptive questions about demographics and the length of time active in LEx spaces as a leader, and nine open-ended questions allowing for qualitative responses about LEx leadership, learning, pathways and change. The qualitative approach to the survey was chosen to complement the broader project and allowing people to respond to questions in their own, preferred language. Participants did not have to answer all questions to move through the survey, subsequently the number of responses to each question varied.

Participants were aged 18 years or above and had lived/living experience of mental health related distress or someone who is caring for a person experiencing mental health related distress and active as a leader in contributing to improving services, community awareness, advocacy and policy, peer networks and support, community education or advisory roles. A recruitment strategy was enacted and disseminated through mental health and LEx NGOs nationally via email lists and social media sites inviting participants with LEx and leadership experience to complete an online survey. Permission to promote the surveys was sought from each NGO in respect to promoting through their membership networks.

48 responses were collected between 29/10/2020 and 18/12/2020. SurveyMonkey descriptive analysis was used for the demographic results, while NVivo was used for analysing the text-based responses, and for recording meaningful and prevalent themes. The work up of questions and interpretation of data was guided by a systems approach², with a focus on cultural, structural and relational aspects of the system in which LEx leadership takes place.



People participating

Of the people participating:

Cultural background / identity membership

- 3 identified as Aboriginal Australians
- 31 as Caucasian background Australians
- 7 as Australians of CALD background
- 6 identified as part of LBGTIQ+ groups

Age

- 1 was under 25 years
- 2 were 65 years and older
- 45 between 25 and 65 years

City / Rural

- 5 lived in regional cities
- 5 lived in rural settings
- 38 lived in capital cities

In terms of LEx:

- 44 Had LEx of distress and/or mental health issues
- 22 had LEx of sexual abuse and/or violence
- 22 had LEx of childhood trauma
- 20 had used public inpatient mental health services
- 19 had LEx of partner or family violence
- 16 Lived with a chronic illness
- 16 were carers of someone living with a psychosocial disability
- 14 were living with a psychosocial disability
- 14 had LEx of being under the Mental Health Act (being detained)

Gender

- 3 identified as nonbinary or preferred to self-describe
- 36 female
- 4 male

State

- 24 were from SA
- 7 from NSW
- 6 from ACT
- 9 from across VIC, QLD and WA

- 13 had LEx of intergenerational trauma
- 12 had LEx of alcohol and/or other drug use
- 11 had used a private inpatient mental health service
- 11 had LEx of homelessness and/or housing instability
- 9 were carers of someone living with other disability/chronic illness
- 7 Lived with other disability
- 4 had LEx of being neurodivergent
- 0 had LEx as a veteran or first responder
- 1 had LEx of violent crime

These figures indicate that the respondent's group have a diverse range of LEx and reflects the connections between the experience of mental health issues, childhood trauma, family violence, chronic illness and disability.







Findings

Becoming involved in using LEx for social change

This question was about identifying the different pathways that people followed in becoming active. Responses below indicate pathways of advocacy, peer support work, education and suicide prevention were prominent for people, with community advocacy being the most common. Attending events at consumer or carer orgs was also a feature. Responses suggest that people engaged in multiple activities overall and that all of these need recognition and development for attracting people to LEx activities. It is significant that people may become employed in a LEx position as an initial pathway, without wider grounding in volunteering work.

- 24 became active in community advocacy
- 17 started to mentor others with LEx
- 19 became involved in committees or advisory groups and mental health services
- 17 started attending events at consumer or carer organisations
- 15 became a community speaker or educator
- 14 gained employment in a LEx position
- 14 volunteered in suicide prevention committee or community work
- 8 gained employment as a peer worker
- 6 undertook a peer support work qualification
- 8 became involved through other pathways (volunteering for peer led organisation, study, involvement through disability sector)

Length of time involved in organised LEx.

Responses to this question indicate a spread of 'time involved' in organised LEx spaces, which is a positive pattern for having a mix of new and experienced peers. 19 per cent have been involved for under two years while 54 per cent of participants have been active between five and 14 years, with 15 per cent being active from 15 plus years.

Under 1 year	4 (8.33%)
1-2 years	5 (10.42%)
3-4 years	6 (12.50%)
5-9 years	15 (31.25%)
10-14 years	11 (22.92%)
15-19 years	2 (4.17%)
20 years plus	5 (10.42%)





How would you define, or describe LEx leadership? (47 responses)

The most prevalent themes in describing LEx leadership were the actions of:

- Advocacy and mobilisation for change, transformation and justice.
- Sharing experience, supporting and empowering others.
- Using LEx lens and positioning.
- Creating safe spaces.
- Challenging stigma.
- Educating to raise awareness.

There were other contributions in terms of role modelling recovery, leading the peer workforce, and a challenge that hierarchical leadership in the peer movement is a problematic concept, with one respondent sharing highlighting that relationships should always be horizontal and mutual.

The qualities and skills most prevalent across the responses were that LEx leaders inspire, offer hope, work from empathy, are driven by passion and are effective influencers.

LEx leadership in the area of mental health has the skills to mobilise community consciousness and demand a fair go for others and is able to advocate in micro and macro organizations and institutions³. (LEx leader)

LEx leadership is a role that invites change and transformation leading through one's own story, experience, vulnerabilities and courage. (LEx leader)

The model of leadership I am interested in is shared horizontal power which practices shared networking and multi resourcing, deep consultation and collaboration (and a) shared rotation of leadership roles. It is fully participatory therefore it employs creative ways of participation and networking, sharing of resources and roles, active group meetings, deep listening and creative conversations...Horizontal power creates shared networks of multi leaders, multi resourcing and increases the power of collaboration. (LEx leader)

What are the key messages that you often use to promote the value of LEx and or LEx leadership? (46 responses)

Analysis of key messages used by participants identified four common categories or broad themes of messaging. These were:

The value of lived expertise and perspective; this provides hope for recovery, shared knowledge and experience, skills and strategies, provides insight, promotes empathy for the LEx pathway; the voice of LEx must be heard; people are the experts in their own life and the LEx workforce (LEW) is a service's best resource.

Nothing about us without us: we need to be heard at every table and have representation at all levels, being embedded in service design, operation and evaluation to ensure system accountability, its only 'coproduction' if we say so, we need diverse voices (intersectionality matters).





Messages of recovery: not all treatments work for everyone, be the driver of your own recovery, build knowledge around supportive strategies i.e., boundaries, develop your own support network, there are rewards from LEx.

Messages for services; we are due every consideration, care and dignity, Social and systemic change will be led by LEx advocates, the dignity of risk, mental health is personal and contextual.

Other areas of messaging were related to the value of peer support, the importance of honesty and authenticity, awareness raising of stigma, and specific messages about LEx leadership itself (ensuring diversity of voices, and the need for shared leadership).

Are there different skills and qualities required for LEx leadership within service delivery and peer support as compared to advocacy and systems change efforts? (37 responses).

The responses to this question were significantly varied. Many responses pointed out the importance and centrality of systems advocacy skills and qualities and provided a commentary on these. Where responses did compare the two practice areas, there was acknowledgement of the different skills and qualities involved in being a peer support leader, and the way personal experience is used in peer support and in advocacy work.

There are definitely different skills and ways of using LEx at different levels - it is even more nuanced than just peer support vs advocacy. But neither is more important than the other. (LEx leader)

The language you use is quite different, as is the way you would use your personal experiences to inform your work. The nature of relationships in those two spaces is also a factor in how you operate. (LEx leader)

Absolutely client face to face LEx work is very different requiring very different skills and abilities to the advocacy LEx roles. People with a LEx should be able to access appropriate training opportunities based on the nature of their role - one on one work with clients, group work, advocacy and policy work all require very different skill sets. (LEx leader)

There was also the theme that general skills and qualities reach across both roles and are grounded in peer values.

No, the basic principles and values of peer work and LEx must be the foundation. (LEx leader)

Understanding, passion and compassion for all LExs should be a part of all skill sets. (LEx leader)

Yes, but they are not mutually exclusive... (LEx leader)

Some responses pointed out orientation pathways to help people understand the links between both areas:

I think the pathway should be very similar but have a support work stream and an advocacy stream. Maybe the 'entry level' could be the same for all - like start with an advocacy course that covers the history of the consumer movement, peer values, and maybe a bit of legislation and information about the system and what all the acronyms stand for etc. (LEx leader)





What are the learning / support pathways and networks required for LEx leadership within advocacy and systems change? (35 responses)

As above, there was a wide range of responses to this question, including detail on the skills and qualities required. The evident themes were:

• Accessible training opportunities in advocacy are important, helping leaders gain skills in understanding systems advocacy, identifying targets and articulating solutions, having influence, strategy and communication skills, and the use of personal and collective perspective.

(Advocacy work has) more intensity around courage, vulnerability, self-care – high levels of working with resistance, very high self-awareness, emotional intelligence and understanding how power and identity operates. (LEx leader)

There also needs to be designed some informal training modules designed to teach people with non-governance experience how the government and non-government systems operate and learn what is in their scope of change. (LEx leader)

• Recognition of leaders' growth of skills through informal learning., e.g., reflection on achievements and learning, impact on policy, building networks etc. This is supported through mentoring and supervision.

My personal experience (pathways) has been to connect with key organisations and key individuals within organisations who are interested in supporting LEx. Both national and internationally. People who care about advocating for LEx are passionate about helping others (advocates). (LEx leader)

• Promoting ongoing opportunities for involvement in system and service planning.

All LEW to come together once a year to develop their own service plan and goals for the year greater opportunities for LEW to participate in service planning for an organisation and not just the executive leads. (LEx leader)

• Pathways should facilitate connection and voice of advocacy for diverse groups.

Yes, such as young leadership is different to older generations. Female leadership is different to male. The LGBTQI leadership is very important. CALD communities and Aboriginal leadership bring a unique perspective. (LEx leader)





What are the learning / support pathways and networks required for LEx leadership within peer support and service delivery? (32 responses)

The responses to peer work pathways were generally less detailed than for the advocacy question and were centred on the Cert IV in Mental Health Peer Work. The most prevalent themes were:

- Formal learning in peer support through Cert IV is important to promote programs need to be improved in ensuring authentic LEx led Cert IVs in peer work.
- More funding is required to support these programs and to enable people to access them, including funding/scholarships for places.
- Innovation such as apprenticeship approaches where people start in positions and gain qualifications over time, while in paid positions.

An apprenticeship where people can obtain the Cert IV Mental Health Peer Work whilst working on the ground...I would like it if the Cert IV apprenticeship opened the door to paid LEx work, but then there was also other options to further refine skills in the area - like a diploma, bachelor's etc. I think starting with an apprenticeship prevents socioeconomic barriers that would otherwise get in the way of having fair an equal access to the course. (LEx leader)

Certificate IV non-clinical peer work is an excellent qualification for peer workers working on the ground with clients and there should be increased funding/scholarship opportunities for consumers wanting to use their LEx to empower others. (LEx leader)

What would be your priority topic areas for the development of learning resources which support LEx leadership? (36 responses)

This question was aimed towards understanding which topic areas should be pursued within training and education. Responses highlighted the importance of generating awareness and change through education of non-peers and systems advocacy, as well as managing up and having influence. Being an ally was also a highly rated topic. We were asked to ensure that training and learning are available to leaders in rural areas.

Торіс	Votes	
Educating non LEx people	25	
Systems advocacy skills and policy work	24	
Managing upwards and creating influence	23	
Being an ally to other LEx identity groups	23	
Public speaker and education skills	21	
Co-production processes and facilitation	20	
Systems change models and practice	19	
Consumer or carer expertise and your own story	19	
Advocacy within peer support work	17	
Being an effective mentor	17	
Building your own networks	13	
Working informally, outside of organizational roles		

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Others (see below)



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- $\circ~$ Research to help with evidence base development
- A resource on lateral violence, and other barriers or difficulties within this space (as well as how to overcome them!)
- o Developing project work skills

Possible learning resources:

- ACT Mental Health consumer network
- Advocacy support organisations
- Alternatives to Suicide
- Borderlands Melbourne
- Brook Red and Peer Zone Australia
- Cert IV Mental Health Peer Work
- Governor's leadership program for women
- Icarus Institute
- Indigenous models of consultation and collaboration
- Intentional Peer Support
- LEx research articles
- LEx Australia

- LEx Leadership and Advocacy Network
 South Australia
- LEW Project, Mental Health Coalition of South Australia
- Madness Radio
- Mariposa trails Spanish speaking mental health and wellbeing community initiative
- Peer networking groups
- Safe talk training with LivingWorks
- SAHMRI community engagement
- Suicide Prevention Networks
- The Australian Centre for Social Innovation

 work on mental health
- The Kit Advocacy Manual
- Various LEW frameworks
- Voices Vic

How does being a LEx leader impact on personal recovery? Depending on your setting, are the impacts different in the systems advocacy area compared to peer support and service delivery? (35 responses)

These questions were asked to explore the context of leadership as connected to recovery, in terms of the project exploring the personal and public within leadership activity. The responses indicated that leadership work is rewarding and contributes very significant meaning personally. This was the strongest theme across responses, with many participants highlighting the sharing learning and insights from peers.

All can be incredibly liberating and also require the need for robust reflection and self-care. (LEx leader)

My experience in treatment was profoundly traumatic, and my work as a LEx leader has helped me understand that it wasn't my fault, and that I'm not alone. (LEx leader)

In terms of my identity, I don't see myself as a victim (anymore), I see myself as a survivor, I see myself as a battler and I am proud of how far I have come. But most of all, I just see myself as human - which is something I never thought possible before I connected with peers, I always felt othered. (LEx leader)





A further understanding was that leadership activity is positive for recovery if the right supports are in place.

LEx leadership can have an extremely positive impact on personal recovery if the experience is in a supportive and safe environment. (LEx leader)

Having had over 38+ years as a person with a mental health issue, it has only been in the last 4-5yrs that I have been involved in peer support and attended many conferences and forums. In this time, I did my CertificateIV in Mental Health & Certificate IV in Mental Health Peer Work. In

this short time, I have personally found a real passion to continue in this area which has only strengthened my personal recovery. (LEx leader)

This was in recognition that peers often face stresses relating to inclusion and feeling valued in their role, and the impact of advocacy and disempowerment over time. There were also a number of references to lateral violence from some participants.

If I feel like I am not valued and my purpose or role in a particular situation is taken for granted has an impact on my recovery and ability to participate. (LEx leader)

A willingness to acknowledge this is also evident, therefore complexities can be transferred onto the LEx learner (they must be the problem) and depending on the disposition of the LEx leader, they may in turn internalise this judgement. (LEx leader)

...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 LEx. (LEx leader)

In terms of the question on impacts from either advocate or peer supporter perspectives, responses pointed towards the above context of having good quality supports in place for each, as each area has its specific demands. There were also references to the importance of supports being LEx led.

...systems advocacy you're are under stronger external pressure to work with high level staff from outside organisations - this can have a negative impact on recovery. (LEx leader)

Yes definitely. Peer support and personal interaction can be more rewarding and more draining. Must ensure support is there. (LEx leader)

I think there are aspects of impact that overlap between peer support and advocacy roles (being marginalised; the stress of insecure employment; seeing and hearing things that take an emotional toll), but advocacy also requires extra courage to stand up and argue the toss, sometimes when you're the only one in the room thinking the way you do. (LEx leader)

How do you personally stay strong in being a voice/leader for change? (36 responses)

This question also speaks to supports and meanings for leadership. Three themes were evident across responses: using a range of self-care practice, commitment to collective mission and purpose, and support and connection with peers. Participants highlight the practices in being prepared, engaging in professional development, connecting with other peers, seeking mentoring are helpful for staying





strong. Other practices include setting boundaries, being self-aware, knowing your own story and knowing when to take time out to self-care (creativity or work adjustments).

Keep my goal in mind at all times and focus on human rights. Remember at all times those consumers who never had a voice and those lost to suicide helps to remain focused and determined. (LEx leader)

Advocating for change and being a witness to this can help your own recovery also. (LEx leader)

I gain strength from helping other people. It validates my belief and my position of the need to advocate for change. (LEx leader)

I make sure to reconnect with my purpose (why) as often as possible. I do this sometimes by mantras (e.g., on the bathroom mirror), sometimes by listening to podcasts or audiobooks, or sometimes by connecting with others in the movement. (LEx leader)

What do you think needs to occur for real change to happen in our mental health and community systems? What is the role of LEx within this? (35 responses)

Five themes were identified to summarise responses to real change and the role of LEx. People's comments also highlighted various barriers and challenges which are well known to many advocates and peers. The themes are:

LEx voices at all levels of influence; more inclusion for consumers, carers and families, more senior peer roles, collective LEx leadership and power sharing to support a bottom up approach to change.

Greater promotion of the LE voice. High level political and legal collectivism, activism, diplomacy that furthers bi partisan support for whole of community change. (LEx leader)

Education and shared understanding; particularly increased education of the non-LEx community, ensuring involvement in university curriculums for mental health disciplines, providing funding for training and research. These should challenge stigma and othering, and create acceptance and space.

People in LEx leadership roles need to continue to push for epistemic justice and equal recognition of experiential knowledge, as well as social justice. This more than justice advocating for an alternative model for understanding distress...it means advocating for people to make meaning out of their own experiences in ways that make sense for them without coercion or imposition. (LEx leader)

Create enhanced leadership pathways: improved access to peer supervision and support, developing LEx peak body as an advocate, collective LEx leadership and building of LEx constituency.

So far LEx leadership has not made use of our knowledge and resourcefulness. Within the LE group there are all the solutions, and lots of energy to design and implement better alternatives...We need the opportunity for all of us to work together, through good networking, shared power, shared resourcing (and) shared leadership. (LEx leader)





Improved sector leadership: this includes executives understanding and valuing LEx leadership and workforces, improved accountability and leading supportive culture.

The upper management must support the real change, real change must be documented and experience should be shared in order to change the mental health culture in SA. (LEx leader)

Service reform and increasing the peer workforce; development of alternative models of crisis support with peer workforces, improved integration of peers within community mental health services, and other community services, improved LEx presence in wider communities.

Peer workers in ED, in community mental health facilities, in acute mental health wards work make such a huge difference in sharing knowledge about the system, listening, advocating for, sharing stories and helping individuals by having an advocate. (LEx leader)

Carer perspectives

It is important to consider the contributions made by participants speaking from a carer perspective to the survey. As there were a low number of specific carer participants (n=4) it was not possible to do a separate thematic analysis of carer input. Rather, a collective analysis was produced while recognising the themes that carer participants contributed to as well as specific references of carer issues in responses. In terms of general contribution, carer participants wrote generic responses about the actions and qualities of LEx leadership, on preferred supports pathways, key messages and strategies for real change.

In response to key messages of LEx leadership, carers contributed most strongly on the theme of the value of 'lived expertise and perspective'.

The voice and experience of real people, who know what is needed to make the service work. LEW are an organisation's best resource. (LEx leader)

People are experts of their own lives. (LEx leader)

On LEx leadership actions and qualities, carer responses were more prevalent on the unique understanding of LEx perspectives, being a strong voice in advocacy, and supporting others.

Using your personal experiences in a way that influences everything you do at work and in the community. Putting on that lens in decision making, working with clients, and advocating. (LEx leader)

Advocacy and system change require the ability to lift the voices of LEx and open doors for others. (LEx leader)

For preferred support networks, mentoring, debriefing, and supervision were the most common focus where carers sought development. The identified strategies for 'real change' to occur were increasing the availability of peer support in community teams and improvements in accountability of services.

For real change to happen, people working in the system need to be held accountable for the way they interact with consumers. (LEx leader)





To have LEx staff in community mental health teams to support real engagement with both the clients and carers and the development of new services. (LEx leader)

The carer specific references provided were focused on encouraging services to improve information provision to carers and families, and better linking to carer supports. Information provision was associated with enhancing carers understanding of mental health conditions, ability to provide support and ability to advocate for improved levels of care.

Reflections and conclusions

Leadership actions and qualities

Findings from the survey describe key actions that are often used to define LEx leadership^{4,5,6}. These are strongly referenced around advocacy, mobilising, and change but also include sharing experiences, supporting, and empowering others, using LEx lens, creating safe spaces, challenging stigma and educating others. The qualities that effective leaders bring to their work are the ability to inspire, to offer hope and empathy, and to be passionate and influential. The two contexts of systems advocacy and the work of leading peer support (in the context of leading peer organisations) were both evident in responses, and there were questions of how LEx leadership needs to be seen as a collective, where mutuality challenges the idea of hierarchical peer relationships within organisations.

The key messages used by leaders were characterised into four categories. These include messaging about the value and uniqueness of LEx, the demand for inclusion and recognition, what recovery is like, and values that guide how services should respond to consumers, carers and families. Identifying the common messages used by leaders may be helpful for training and also enables the movement to consolidate and focus its key communications to decision makers and the broader community^{7,8,9}.

Supports, networks and pathways for leadership

A variety of pathways were evident where people can engage in LEx activity, with the most common being community advocacy, committee and advisory groups, attending consumer or carer organisational activities, mentoring, or becoming a community speaker. Also, a significant number of people saw their formal engagement starting with employment in LEx positions. These patterns suggest that LEx organisations and information networks can benefit from promoting opportunities that span diverse pathways, so that people have accessible information and can see the scope of activity that other LEx leaders are involved with.

This is important given the indication that participants see the leadership requirements of advocacy as distinct to peer support or service delivery, but where both should be grounded in the values of LEx. This approach suggests that distinct pathways towards peer support, community education, service development or systems advocacy need to be seen in the wider context of the consumer movement, so that people are orientated to purpose and values, and understand the different actions and contributions that are possible. The work of ensuring a common platform of learning across different pathways would require coordination between the different organisations involved (e.g., educational providers of peer support work qualification, consumer peak bodies, local health services, policy units and suicide prevention groups).

In terms of the specific pathways of learning, it was clear that participants valued formal and informal means of learning, and that opportunities need to grow across organisations and the system. Within





advocacy, formal training in systems and service advocacy skills is required to help people align their passion and motivation for change toward effective skills and knowledge, while informal mentoring and reflective conversations help to build learning over time. For peer support work, the Cert IV in Mental Health Peer Work was noted as the key formal pathway, with on-the-job learning based on effective peer supervision and mentoring. These supports are well detailed in literature for the LEW¹⁰.

Recovery and leadership

The participants responding to this question indicated overall that LEx leadership activity is highly significant and positive for people in the context of personal recovery. This occurs in the context of shared learning, purpose and activity. Working alongside and learning with peers was a strong theme in the responses. As recorded in the literature, participants indicated that the positive experience of LEx work required effective supports and recognition from organisations and co-workers. Stresses from stigma, being marginalised, or the emotional tolls from advocacy and peer support¹¹ were highlighted as factors which undermined positive impacts of leadership and required organisational responses.

Actions for systems change

There were five areas of change identified across the survey responses. These included actions for 1) ensuring LEx voices at all levels of influence; 2) improving education and shared understanding about the LEx movement; 3) enhancing LEx leadership pathways; 4) improved sector leadership; and 5) service reform/increasing the peer workforce. These are actions which require change at organisational and policy levels, including decision making and team cultures. Participants saw the role of LEx leadership as leading education and the development of frameworks to guide understanding and practice, and the growth of the peer work force.

It is significant that improved sector leadership was a theme in responses as the role of executive leaders in promoting successful peer worker implementation, and consumer leader recognition has been highlighted in the literature¹⁰. Executive leaders can lift visibility, promote acceptance, communicate outcomes, encourage stakeholder and funder buy in, and direct resources for infrastructure^{12,13}. The action of enhancing LEx leadership pathways illustrates why systems level thinking and change is essential. Existing learning, employment and volunteer pathways occur within and across organisations, including educational institutions, non-government providers, public health services and policy units. Consumer and carer led organisations also provide training, and establish the context of advocacy goals, and the aspirations for change⁸. Coordinated action across these organisations will be central to ensure the pathways are workable for emerging LEx leaders.

This report has summarised themes and findings from an online survey completed by LEx leaders in SA and other Australian states and territories. The range of questions for the survey were broad and designed to gather perspectives on different aspects of leadership. As the survey had a low number of responses (n=48), there are limits to the depth and data saturation achieved for identifying themes, compared to a survey gaining a higher number of participants. In this respect, the report has focused on the themes that were most prevalent and meaningful to the research questions and the ALEL project. The results of this survey provide significant value to the project and to leaders working on systems development in the LEx area.





References

- 1. Cordeiro, L, & Soares, CB 2018, 'Action research in the healthcare field: a scoping review', *JBI Evidence Synthesis*, vol. 16, iss. 4, pp. 1003-1047.
- 2. Kania, J, Kramer, M, & Senge, P 2018, *The Water of Systems Change*, FSG, Boston.
- 3. All quotes in this report are from survey responses.
- 4. As described by consumer writer Mary O'Hagan 2009 and also found in nursing literature i.e., Stewart et al., 2019.
- 5. O'Hagan, M 2009, 'Leadership for empowerment and equality: A proposed model for mental health user/survivor leadership' *Journal of Leadership in Public Services*, vol. 5, iss. 4, pp. 1-13.
- 6. Stewart, S, Sholz, B, Gordon, S & Happell, B 2019, "It depends what you mean by leadership": An analysis of stakeholder perspectives on consumer leadership', *International Journal of Mental Health Nursing*, vol 28, iss. 1, pp. 339-350.
- 7. Consistent messaging is an important consideration for consumer organisations and peaks. See Gee, McGarty & Banfield 2015, and Janzen et al. 2007.
- 8. Gee, A, McGarty, C & Banfield, M 2015, 'What drives systemic mental health advocates? Goals, strategies, and values of Australian consumer and carer advocacy organizations', *Sage Open*, vol. 5, iss. 4, pp. 1-8.
- 9. Janzen, R, Nelson, G, Hausfather, N & Ochocka, J 2007, 'Capturing system level activities and impacts of mental health consumer-run organizations', *American Journal of Community Psychology*, vol. 39, iss. 3-4, pp. 287-99.
- 10. Byrne, L, Roennfeldt, H, Wang, Y & O'Shea, P 2019, "You don't know what you don't know": The essential role of management exposure, understanding and commitment in peer workforce development', *International Journal of Mental Health Nursing*, vol. 28, iss. 2, pp. 572-581.
- 11. Byrne, L, Roper, C, Happell, B & Reid-Searl, K 2019, 'The stigma of identifying as having a lived experience runs before me: Challenges for lived experience roles', Journal of Mental Health, vol. 28, iss. 3, pp. 260-266.
- 12. Mulvale, G, Wilson, F, Jones, S, Green, J, Johansen K, Arnold, I & Kates, N 2019, 'Integrating mental health peer support in clinical settings: Lessons from Canada and Norway', *Healthcare Management Forum*, vol. 32, iss. 2, pp. 68-72.
- 13. Shepardson, RL, Johnson, EM, Possemato, K, Arigo, D & Funderburk, JS 2019, 'Perceived barriers and facilitators to implementation of peer support in veterans health administration primary care-mental health integration setting', *Psychological Services*, vol. 16, iss. 3 pp. 433-444.
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