

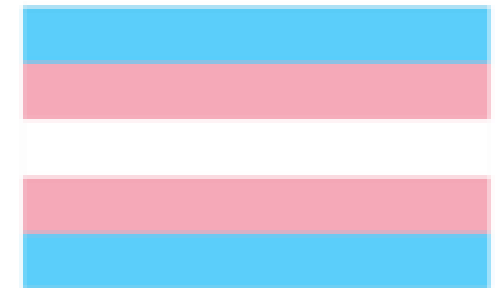
Talking About Leadership: Research Findings from the Activating Lived Experience Leadership (ALEL) Project

TheMHS 2021 | Mark Loughhead (UniSA) & Ellie Hodges (LELAN)



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About the Activating Lived Experience Leadership (ALEL) Project

www.lelan.org.au/alel



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LELAN and UniSA are partners for the Activating Lived Experience Leadership (ALEL) Project

The purpose of the ALEL Project is to examine and describe how lived experience (LEx) advocacy and leadership embedded within the mental health ecosystem can be defined, recognised and utilised in South Australia



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research questions

- What are the reasons why LE leadership and advocacy is not well recognised, acknowledged or enacted by the health system?
- What are effective strategies for embedding LE leadership focused education, thinking and resources within communities and the South Australian mental health eco system?
- What do people with LE say is needed in the design of training resources and networks to guide and support LE advocacy, representation and leadership?
- What are understandings of the impact of LE advocacy and representation on individual recovery from mental health issues including active participation in broader areas of life?

the research activities so far

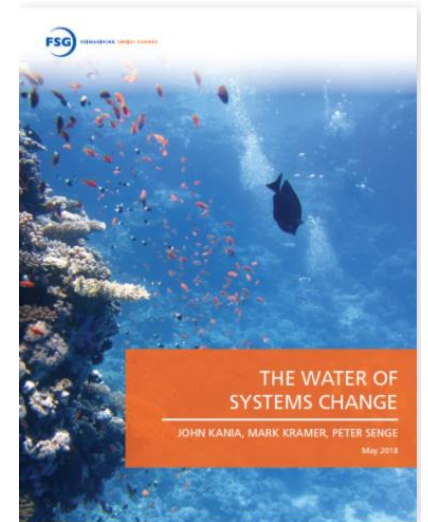
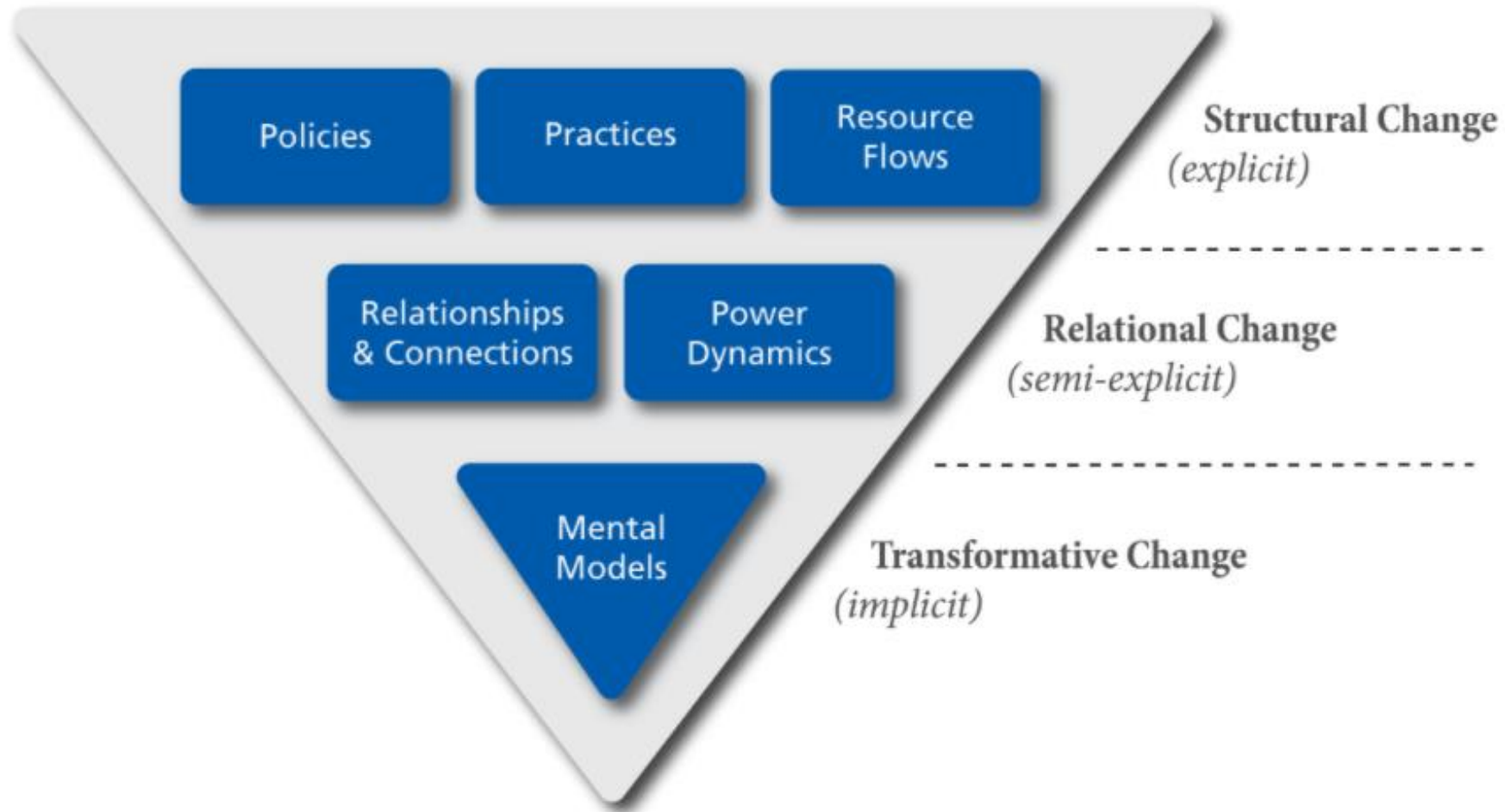
- Research Approach - Participatory Action Research
- Establish Project Advisory Group – LE and other sector leaders
- Focus groups with people active in LE movement – advocates, peer educators, LEW +, Intersectionality focus (31 participants)
- Online forum to discuss initial round of focus group findings
- Round 2 focus groups to reflect and explore networks, support and learning with same participants (15 participants)
- Interviews with sector leaders (14 participants) public MH and NGOs, Rural, Suicide Prevention, some lived experience
- Online qualitative survey, available nationally – (48 participants)
- Other project activities including a leaders/ ally's community of practice, research and systems change workshops, SA sector leaders summit x 2
- <https://www.lelan.org.au/alel/>

analysis of data and information

- Lived experience and reflexive – standpoint research with a system changes focus
- LE leadership notions inclusive of personal experience and experience of caring – watchful of how this played out in data collection and analysis
- Intersectional focus – inclusive of peer leaders active in cultural, LGBTIQ+ and ability/ experientially diverse spaces

- Each data set thematically analysed within NVIVO. Mind maps and summary findings shared for reflection and comment (eg PAG)
- Lived experience perspectives data set and sector leaders data kept separate
- Key documents to include 'Road Map for Systems Change' and 'model of leadership'. followed up by academic papers

Six Conditions of Systems Change



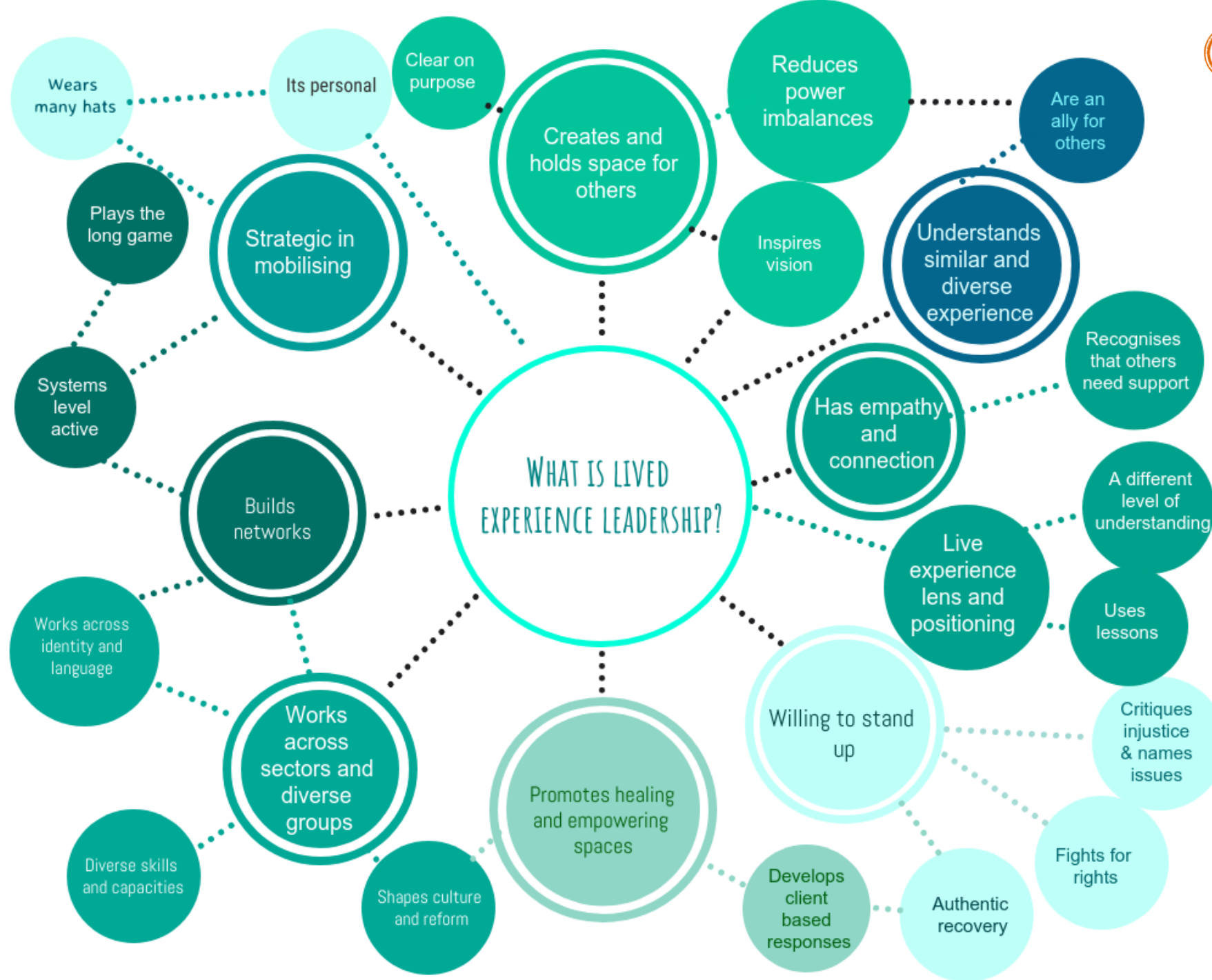
Emerging Findings from LEx Leaders

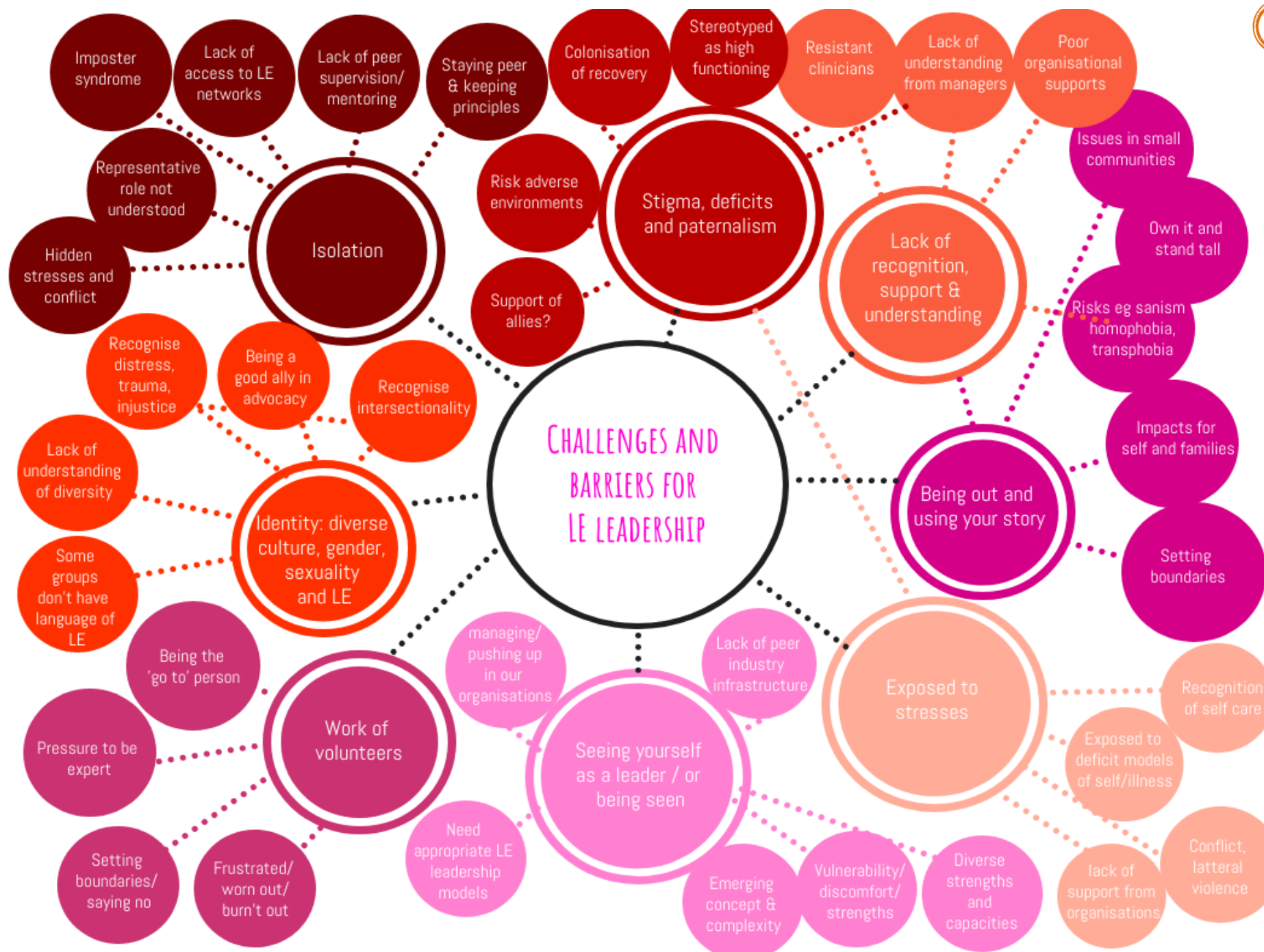


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'I get this feeling that lived experience is a really little box, and so if you surpass the assumptions and stereotypes about that box you're considered not being in it anymore'.

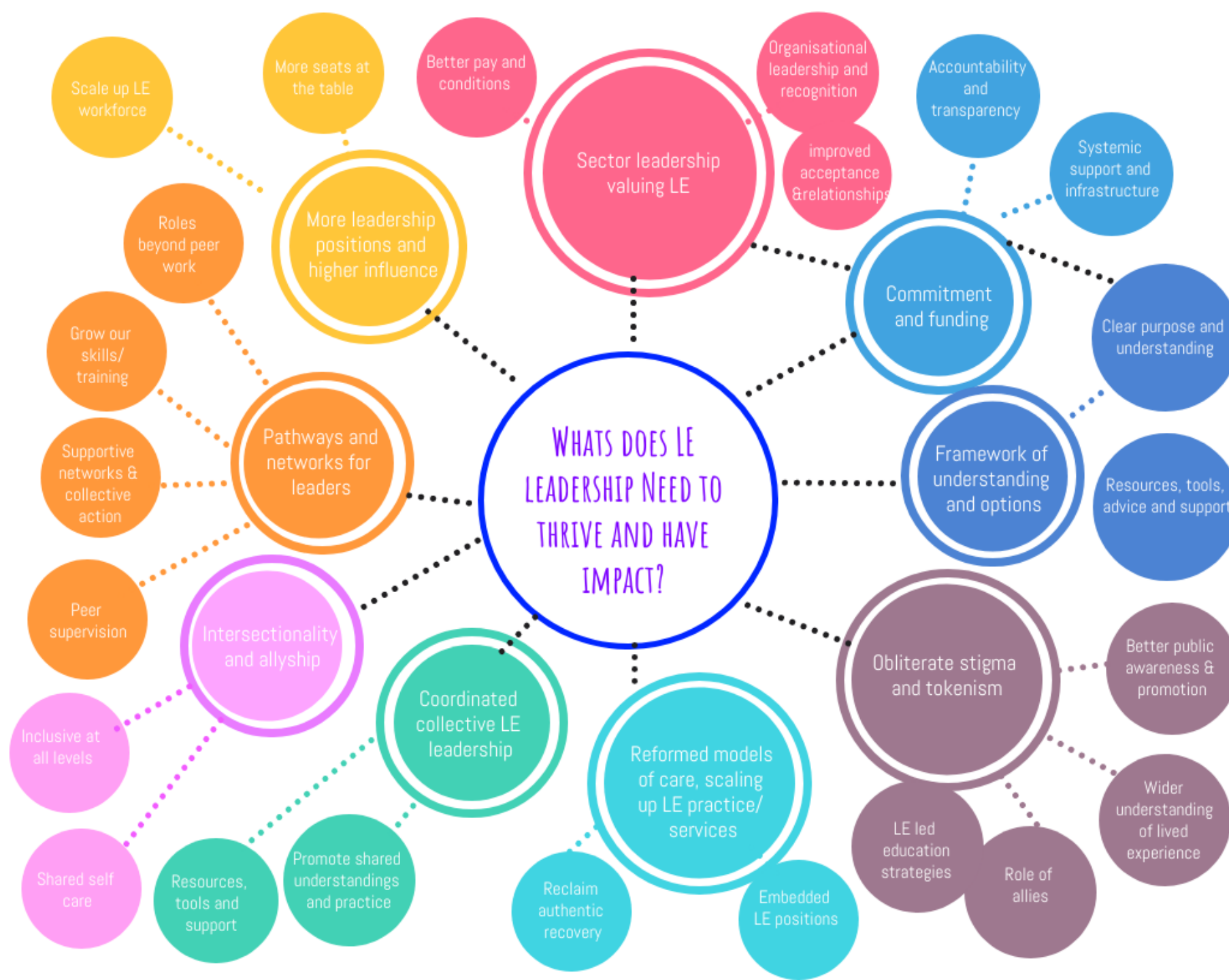
'the labels of high functioning being used to describe my experience of my lived experience and I don't think the intention is to be dismissive, but I already feel I have that imposter kind of feeling anyway, so when that label gets attached to me it does make me feel uneasy'.



'We do, we need more options, we need more – we also need a lived experience framework so we know how our roles are governed and what's best practice and what training should we have and what kind of things can we do in our role and how can we be innovative, and all those kinds of things'

'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'.

'Especially in government, we feel like there's no one above us, there's no one we can go to really, especially navigating all the bureaucracy stuff that we have to. So just people at every level I think would help us thrive and being able to move through the levels'.



‘How do we create real pathways for people with lived experience outside of mental health service delivery, perhaps, where it is maybe CEO roles, other leadership roles, potentially outside of mental health services, full stop, and into other organisations and things where it can be of value, but in a really authentic proper way where it’s not just, oh, we need to tick a box’

‘I think the resolution for me has, or the learnings I’ve had, is making sure you have a supportive network around you because the resilience, I’ve found in the end I was the lone voice and that is a very lonely place to be. The stronger I got the, yeah, the lonelier I got so I learnt, yeah.... so having a supportive network of people who are doing the same thing from the same group is absolutely the way to survive that level of resistance that we’re going to encounter because I’m still (experiencing) the paternalism, the stigma, the silence, the stereotyping, it may not be extreme but it's still there..

What we Have Been Noticing



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lived
experience
leadership is
an emerging
concept ... it's
complicated

- Complexity of the leadership space - relationships, contexts and dynamics to work through
- Personal journeys within organisational and public life – confronting discriminatory social paradigms
- Reflects social movement leadership
- Sector/ Service leaders can see LEx leadership through different perspectives – peer support work, involvement, community development

there are many
challenges and
barriers to LEx
recognition,
being valued
and having
influence

- Forms of stigma/ assumptions on identity are linked to limited opportunities for leadership / lack of suitable models of leadership
- LEx leaders carry 'internal' burdens and stresses that reflect external/ power dynamics and relationships. Leaders have to work through these for meaningful voice, inclusion and action
- LEx and sector leaders overlap on identifying similar key challenges and barriers
- There are a range of strategies which are favoured for strengthening leadership capacity across the movement, within organisations and at the systems level (thrive and impact)

what is needed in SA

- SA needs a clear, visible and strong commitment from government and relevant agencies to develop LEx leadership across 4 key areas
 - Governance and sector leadership level
 - Development of LEx pathways and networks for collective leadership
 - Reformed models of care building on LEx methodologies
 - Growth of the LEx workforce

what is needed in SA

- Changes in culture, structure and resource flows are required for each of these areas
- An independent entity, such as LELAN, required as a backbone to support recognition, valuing and embedding and prompt sector leadership
- A 'road map' to identify how to translate our findings and SA leader commitments into action
- A phase two for the project to support the above

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with us