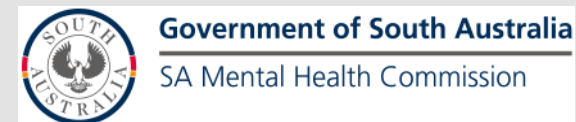


# Early Research Findings and Reflections: seeking comment and discussion

Activating Lived Experience Leadership (ALEL) Project

Ellie Hodges, Mark Loughhead & Heather McIntyre  
[November 2020]



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

We are seeking further comment and input on the early findings and what we have been grappling with



## the research activities so far

- We held 7 first round focus groups with 31 people who self-identified as 'LEx leaders'
- We followed up with 4 second round focus groups to identify preferred support and learning pathways, networks and learning topics. 15 LEx leaders attended these groups
- LEx leaders have had access to an online forum where they can review emerging themes, contribute additional reflections and interact with other participants
- We interviewed 14 South Australian 'Sector and Service Leaders'. These included leaders from NGO's and LHNs: CEO's, Directors, Managers, and others. Some were in Country SA and some identified with having lived experience



# about what we have been hearing so far

- We have summarised key themes and ideas from LEx leaders and sector and service leaders in the following mind maps.
- There are two sets of maps – one for each population group.
- Some ideas appear on more than one mind map
- Some relationships between ideas/themes are indicated, many more links could be added



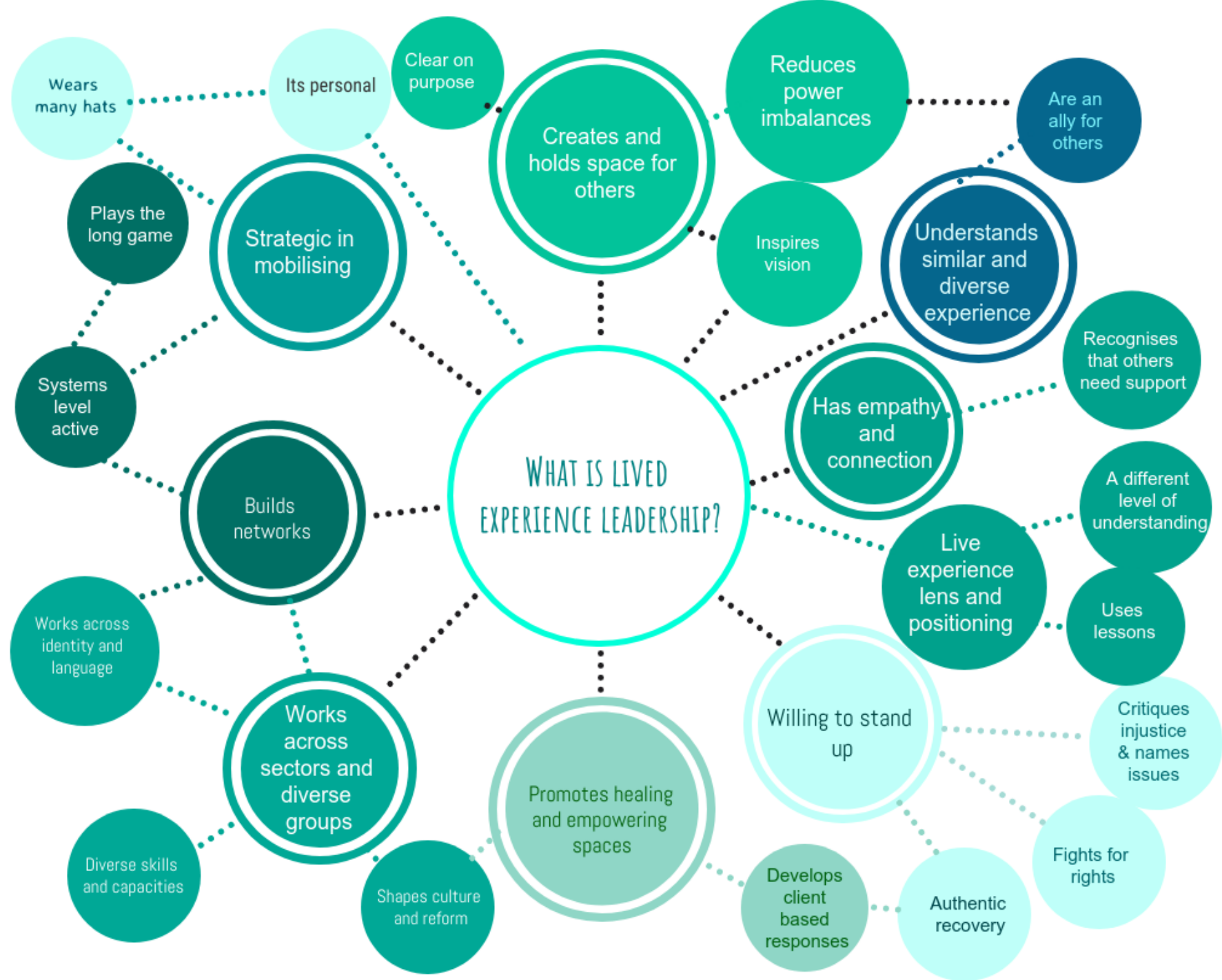
We are inviting comment and discussion about these findings, and we will look to work collectively to identify possible 'systems change actions' for SA

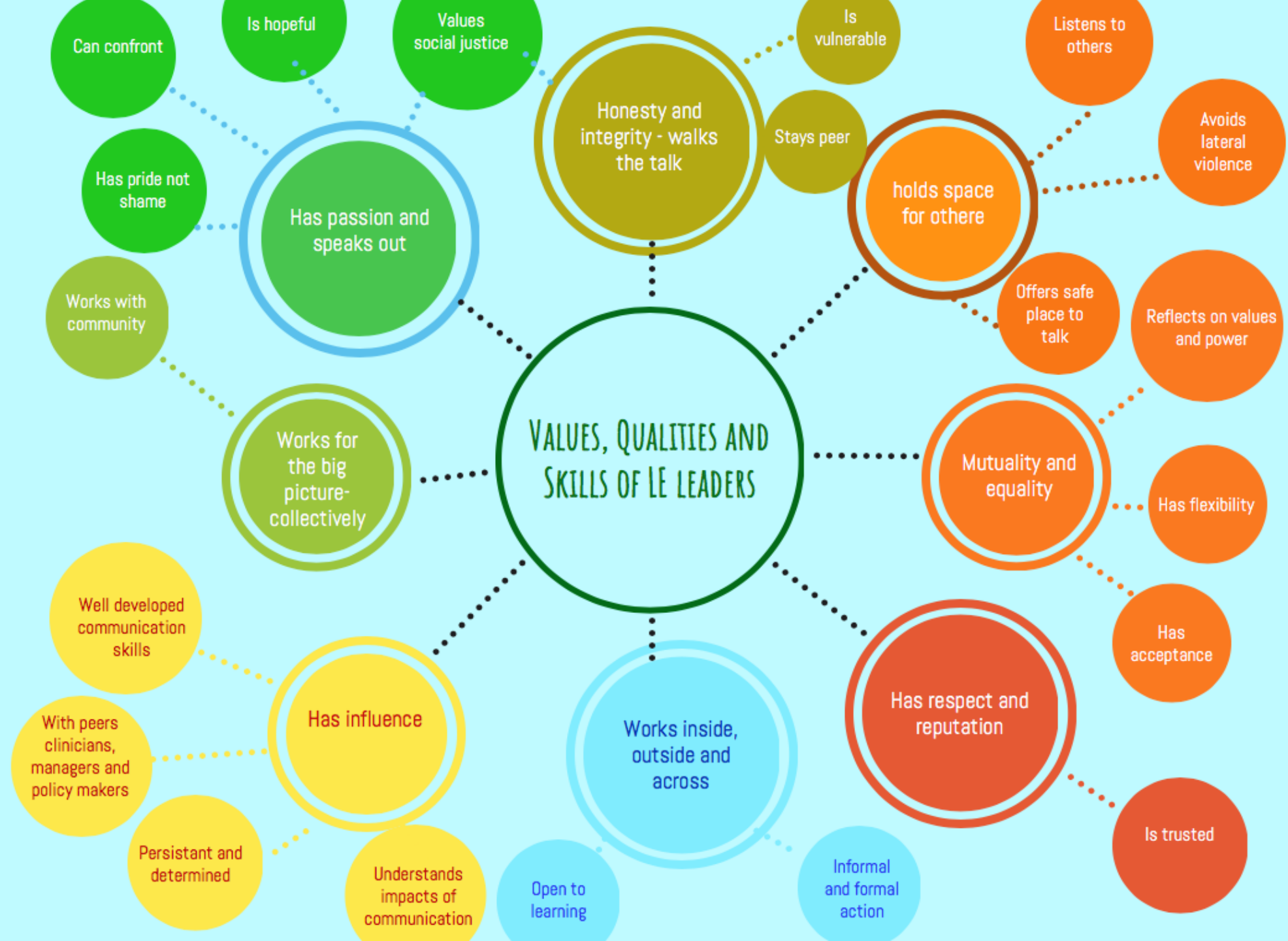
- What stands out from the mind maps for you?
- Are there experiences and insights that need to be added?
- Do the mind maps effectively communicate the world of lived experience leadership and your engagement with it?
- Are there particular ideas/themes that intrigue you and need to be unpacked more?



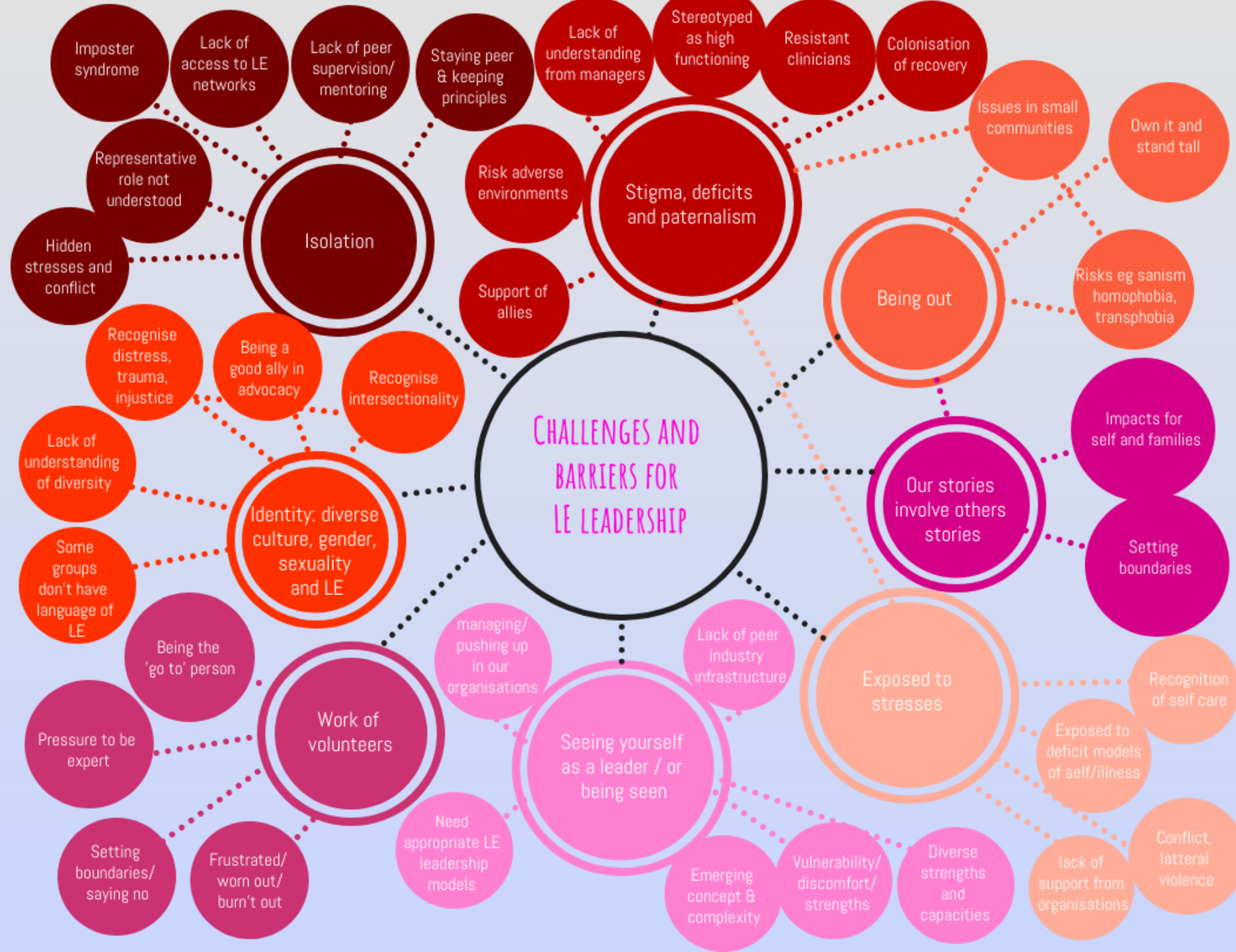
# Early Findings from Focus Groups with LEx Leaders

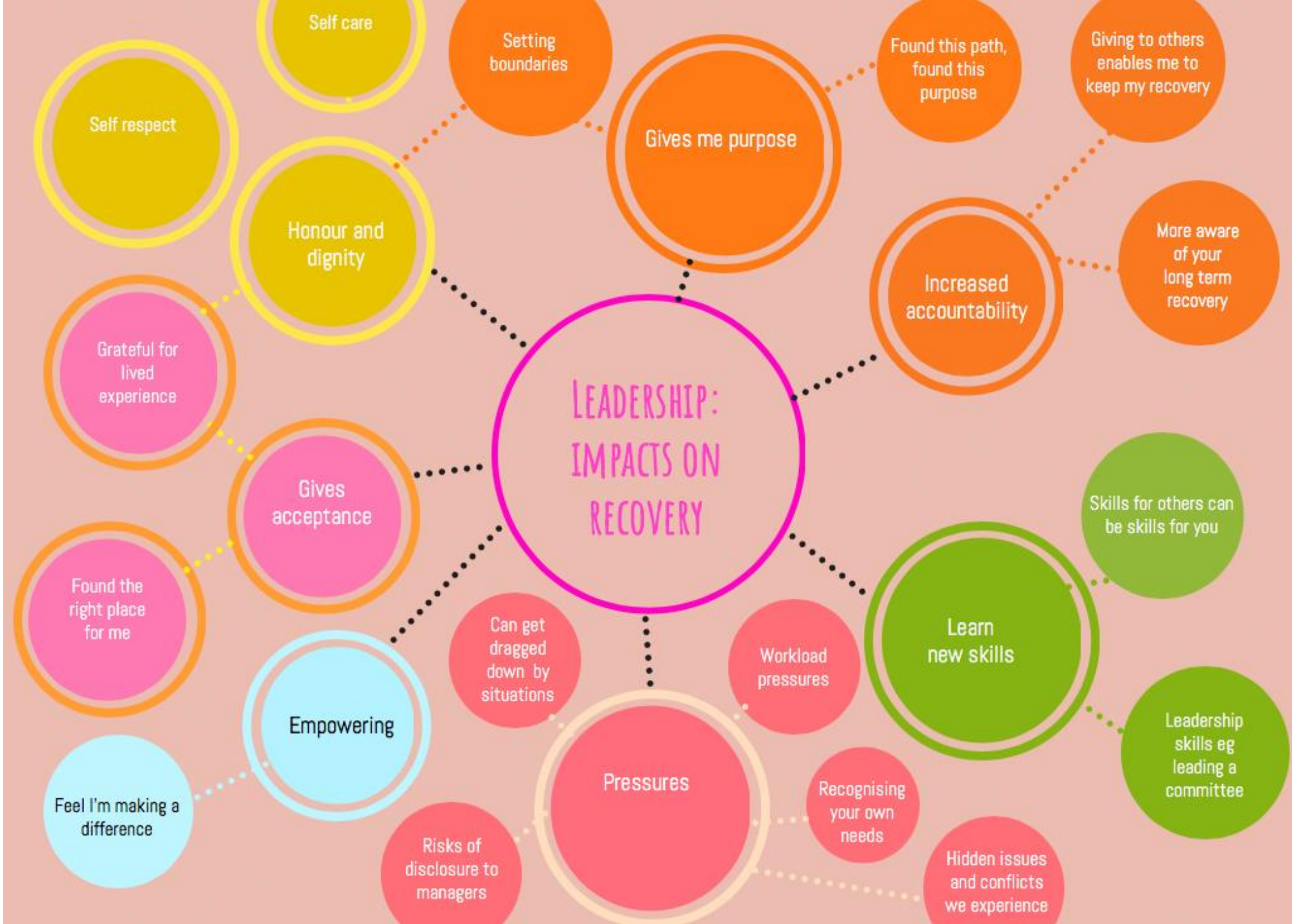


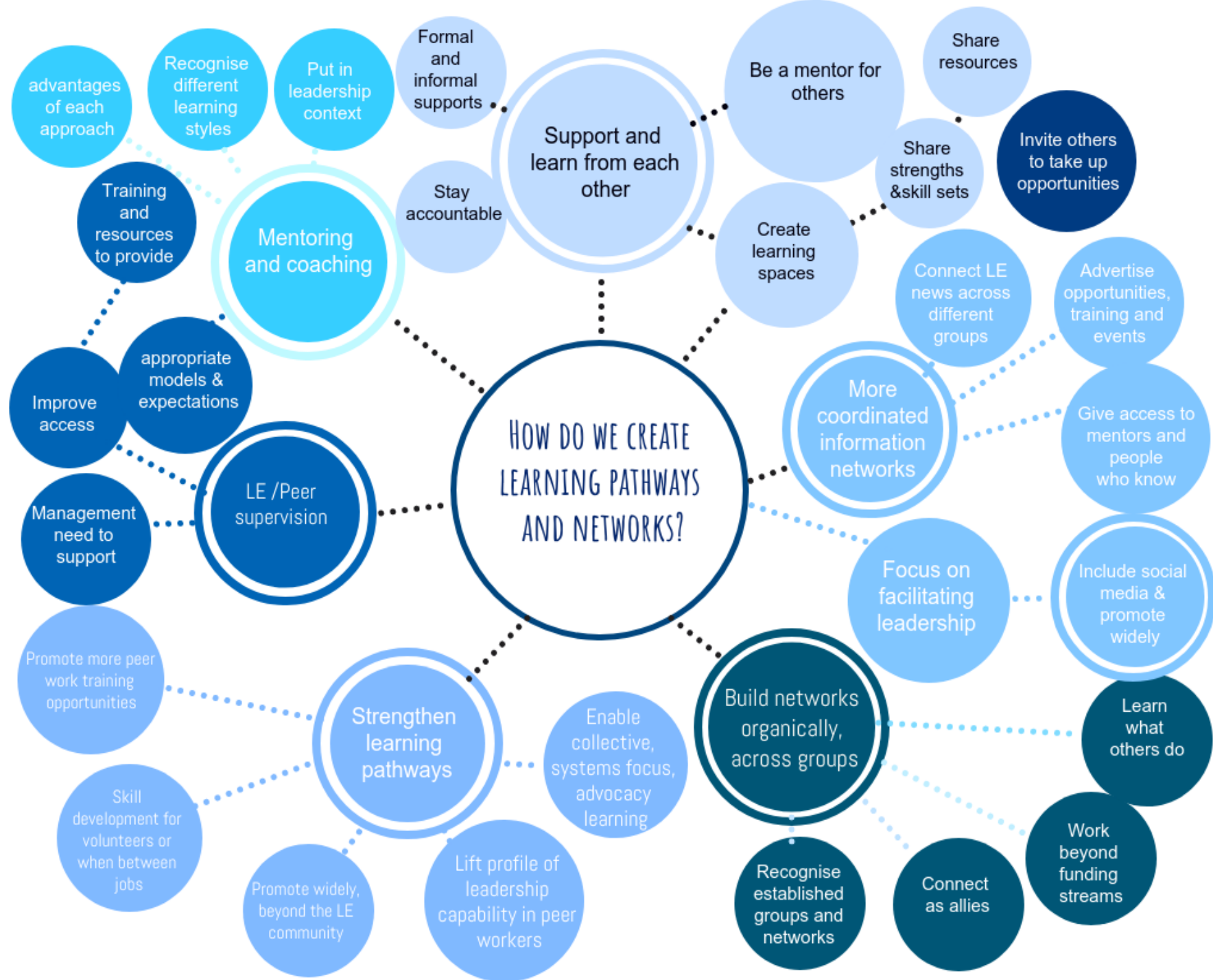




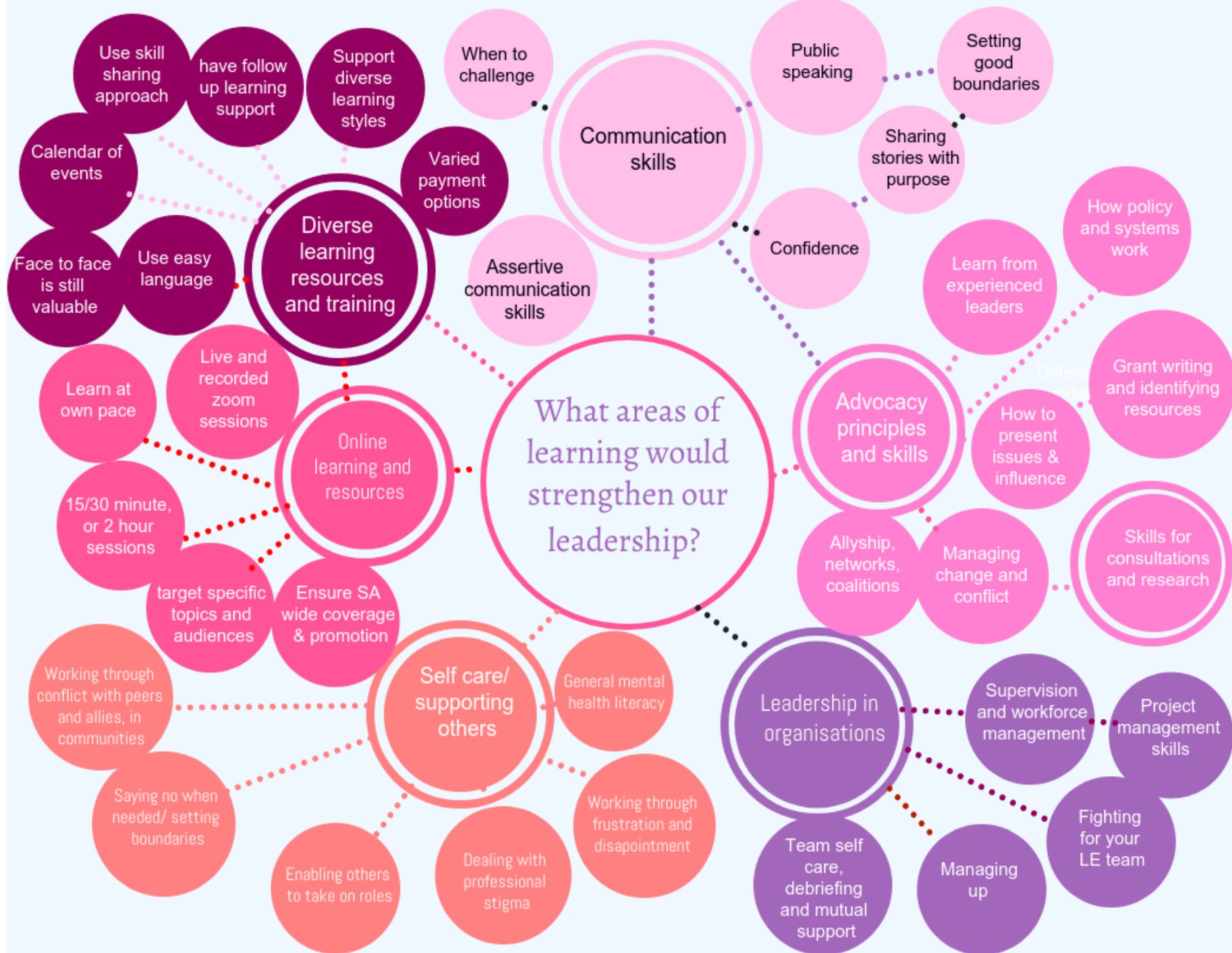


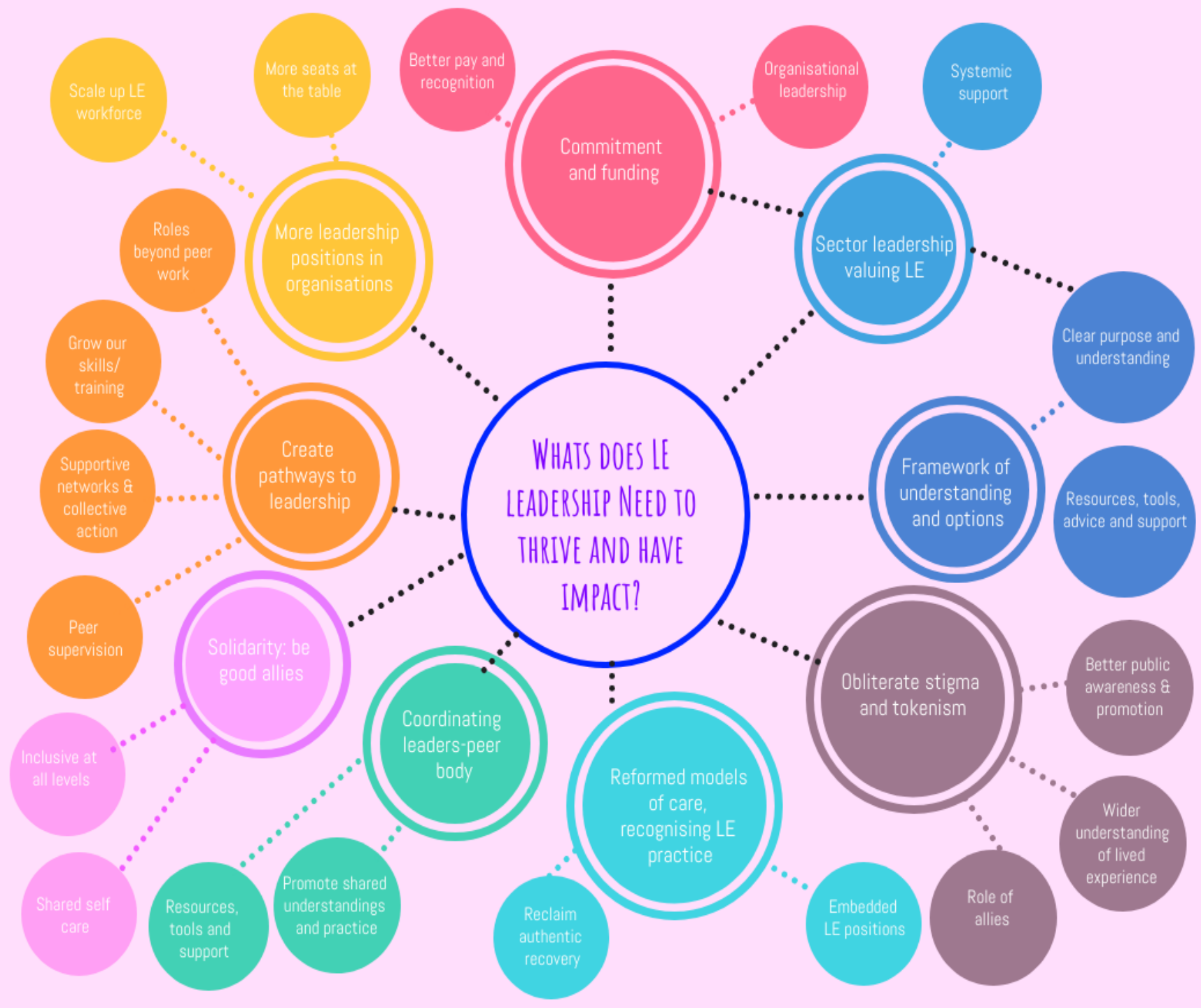












# Early Findings Sector and Service Leader Interviews









LEADS TO







# What the Project Team have been Noticing



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

- Being in the leadership space is often complex; with an array of relationships, contexts and dynamics to work through
- LEx leadership is driven by personal journeys and interests in seeking change, sharing learning and promoting peer environments
- It brings the personal into organisational and public life in unique ways, and requires the courage to confront discriminatory social paradigms on mental health and personal identity
- It also reflects social movement leadership
- Sector/ Service leaders can see LEx leadership through different perspectives, seeing it about recovery or peer support, through the need to consult and involve, or through a community development approach



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

- These occur within organisations, reflect ongoing forms of stigma and discrimination and are linked to limited opportunities for leadership / lack of suitable models of leadership. 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. We are summarising these as our key actions
- It is clear that more work needs to be done





## where SA is at with lived experience

- Organisational and community understandings of LEx involvement and leadership are immature. There are examples of good work across places, services and networks
- Across sector leaders, there is a focus on either involvement, engagement or the peer workforce, rather than a developed understanding of the potential of LEx leadership for transforming the way policy, systems and organisations are produced and delivered. There is limited knowledge how to apply, support, develop or embed it
- Promising work is occurring in the suicide prevention area, as networks and leading coordinators take a community development approach, which can work to empower LEx leaders to act in local settings and environments, rather than within service and organisational hierarchies



## where SA is at with lived experience

- Pathways for people with LEx, in both peer work roles and advocacy/representative roles, are minimal and often defined by services and systems rather than by the LEx community aligned with our values and approaches
- Amongst sector leaders, there is interest in how people with lived experience in non-designated roles and positions, who are not 'out', are seen as part of the lived experience community, and can contribute to organisational or systems development
- Services alone will not make the changes we need for LEx to truly be recognised, valued and embedded. LEx too easily gets lost in the 'burn and churn' of the system, where power and decision making control still is held by providers (rather than shared)



# what is needed

- SA needs a clear, visible and strong commitment from government and relevant agencies to developing LEx within services and with the LEx community. Changes in culture, structure and resource flows are being identified through our research and consultation
- An independent entity, such as LELAN, to serve as a backbone organisation for the development of LEx, to support its recognition, valuing and embedding. We have been told that such work needs to be someone's core business, to build capacity and prompt sector leadership
- A greater focus on by, for and with the LEx community. Enhancing the project's work in building stronger skills, networks and opportunities to nurture and demonstrate leadership and solution ideas that we collectively decide are important
- 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





please send your comments and insights  
or any questions you have to  
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with us

