

Early Findings and Reflections: Seeking Further Comment and Input

Activating Lived Experience Leadership (ALEL) Project

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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

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



the research activities so far

- We have held seven first round focus groups with 31 people who self-identified as 'LEx leaders'
- We are part way through second round focus groups with the same LEx leaders
- LEx leaders have had access to an online forum where they can review emerging themes, contribute additional reflections and interact with other participants
- We are in the middle of individual interviews with sector leaders



Early Findings from Focus Groups with LEx Leaders



about what we have been hearing so far

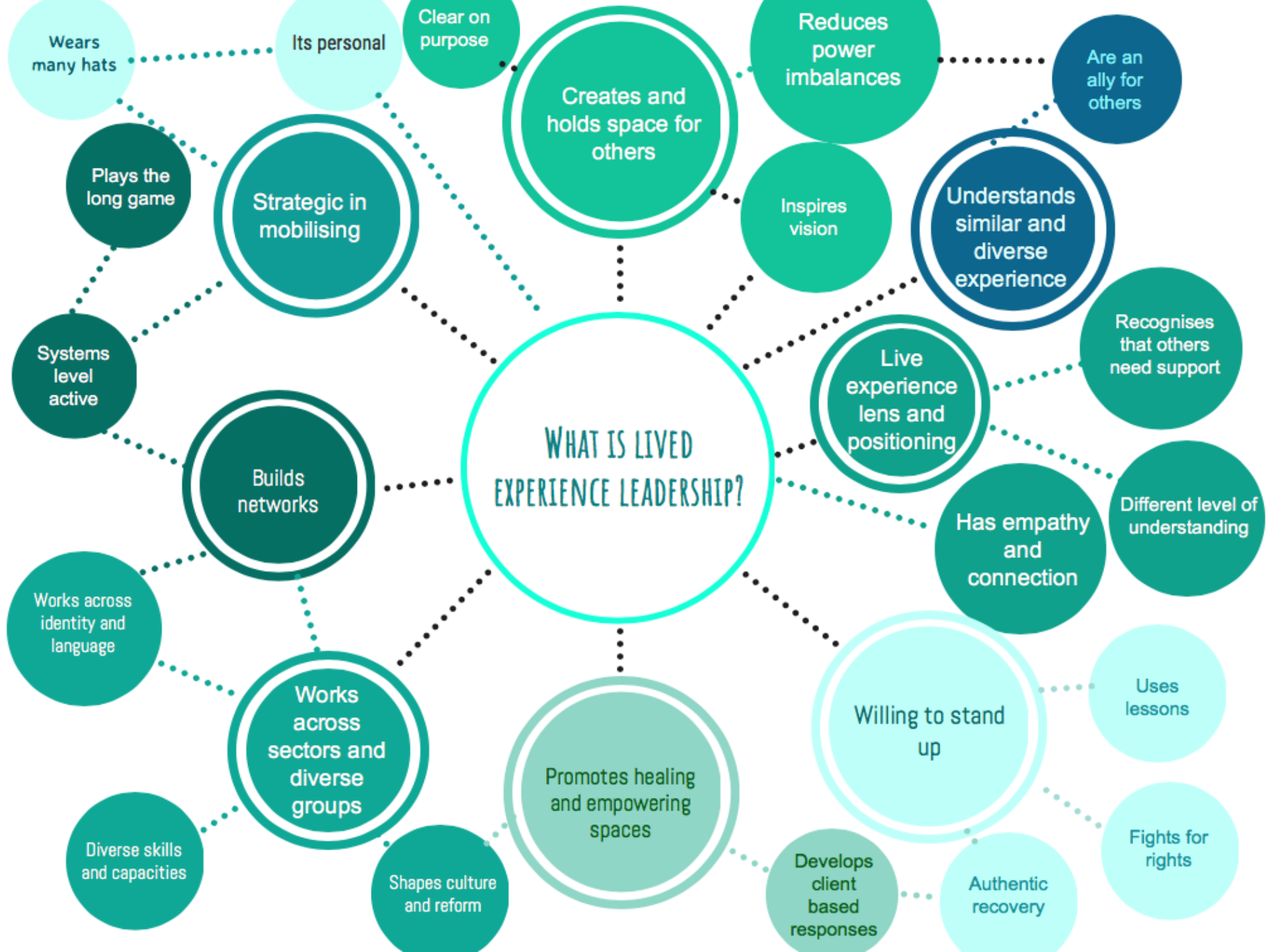
- We have summarised key themes and ideas from LEx leaders in the following mind maps
- Some ideas appear on more than one mind map
- Some relationships between ideas/themes are indicated, many more links could be added

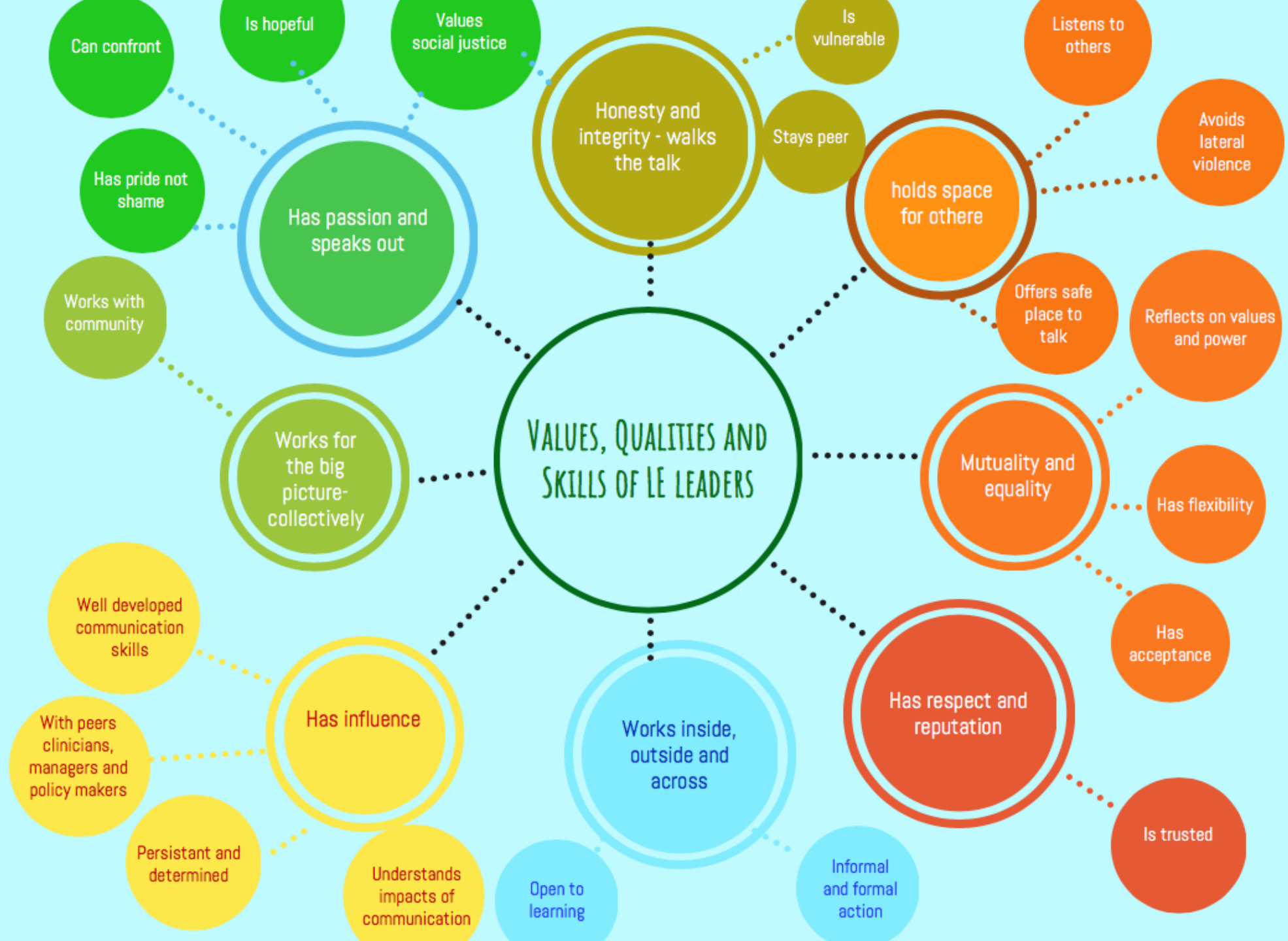


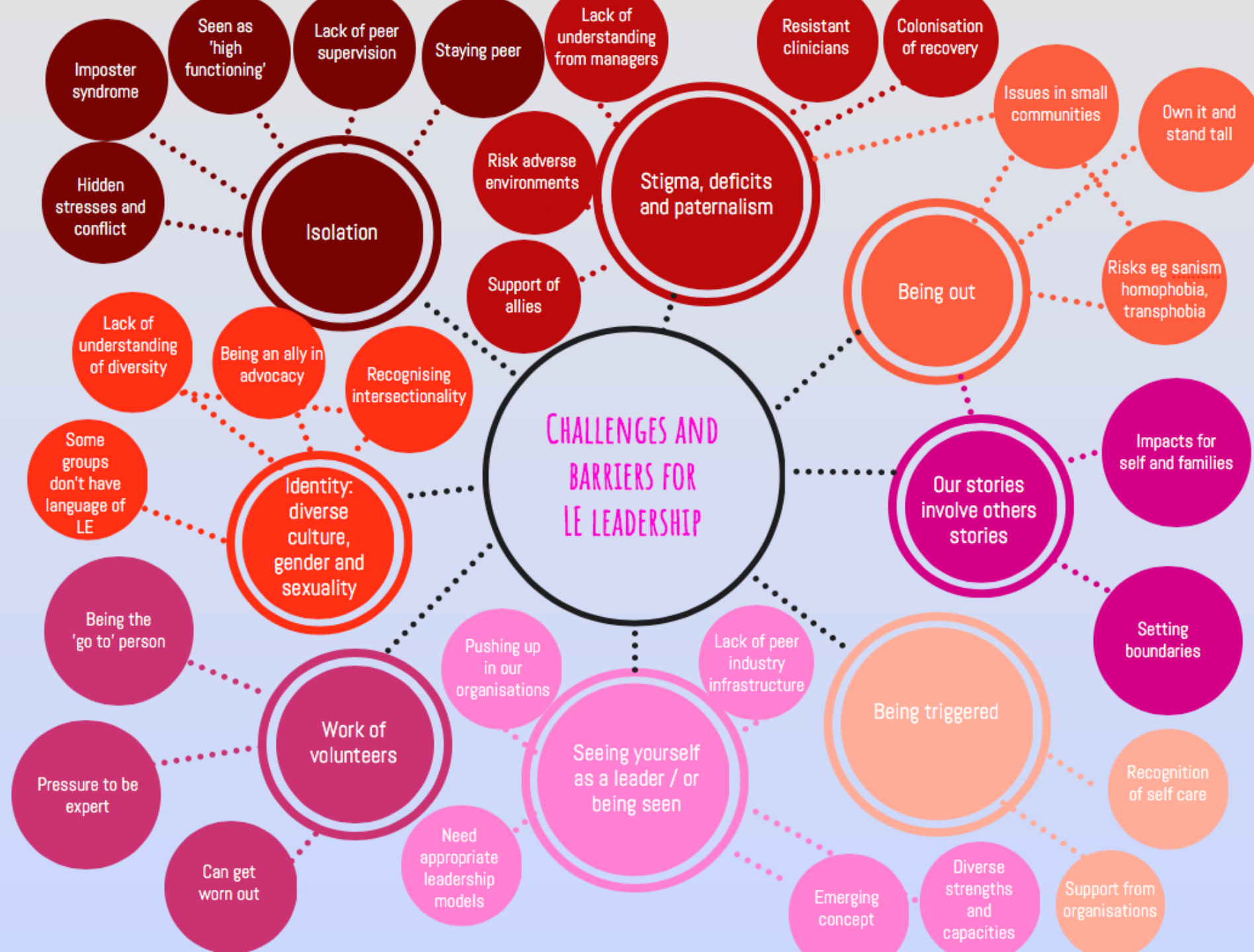
We are inviting comment and input from more people about the emerging themes, in particular:

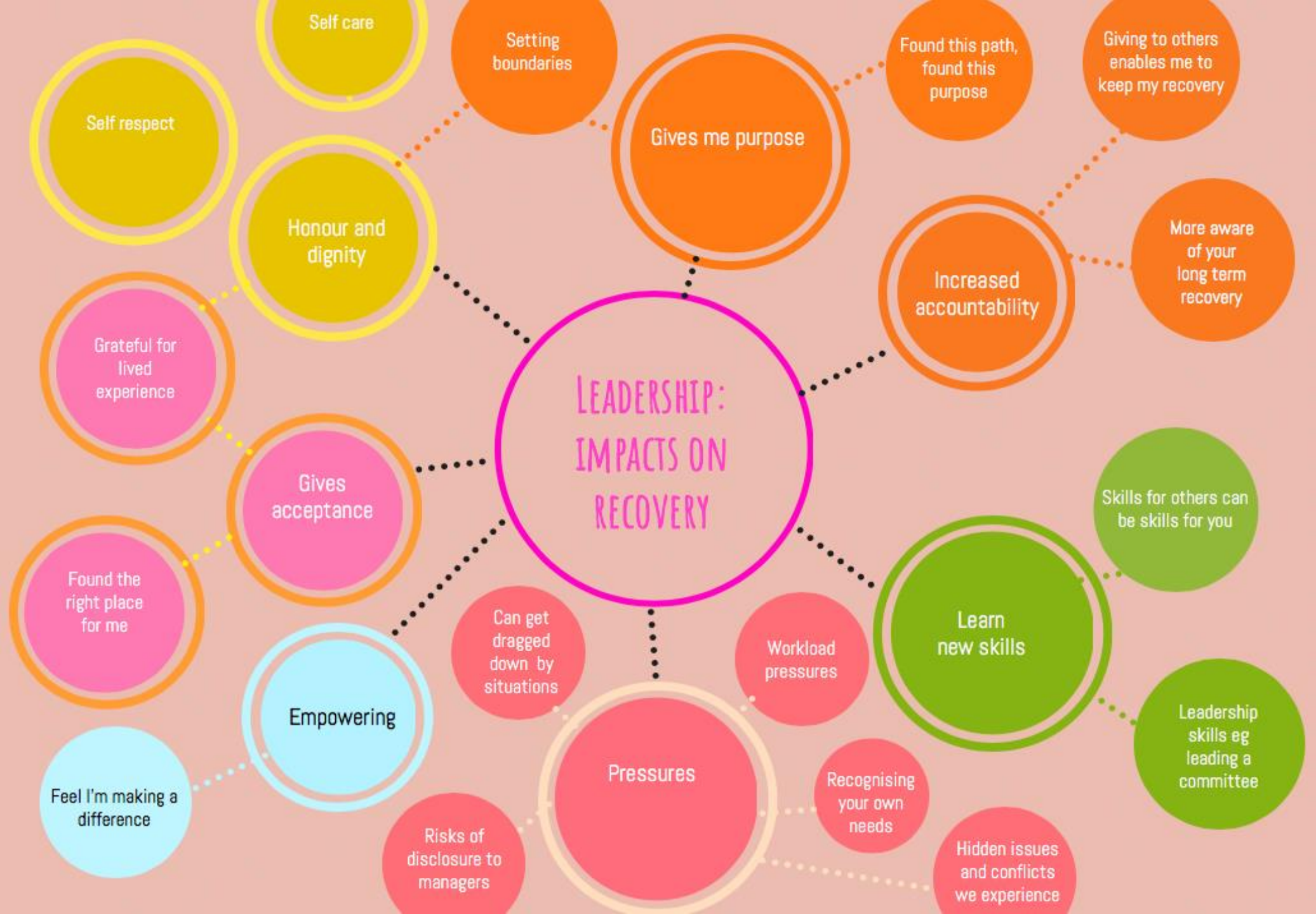
- What stands out from the mind maps for you?
- Are there experiences and insights that need to be added?
- Do the mind maps effectively communicate the world of lived experience leadership?
- Are there particular ideas/themes that intrigue you and need to be unpacked more?

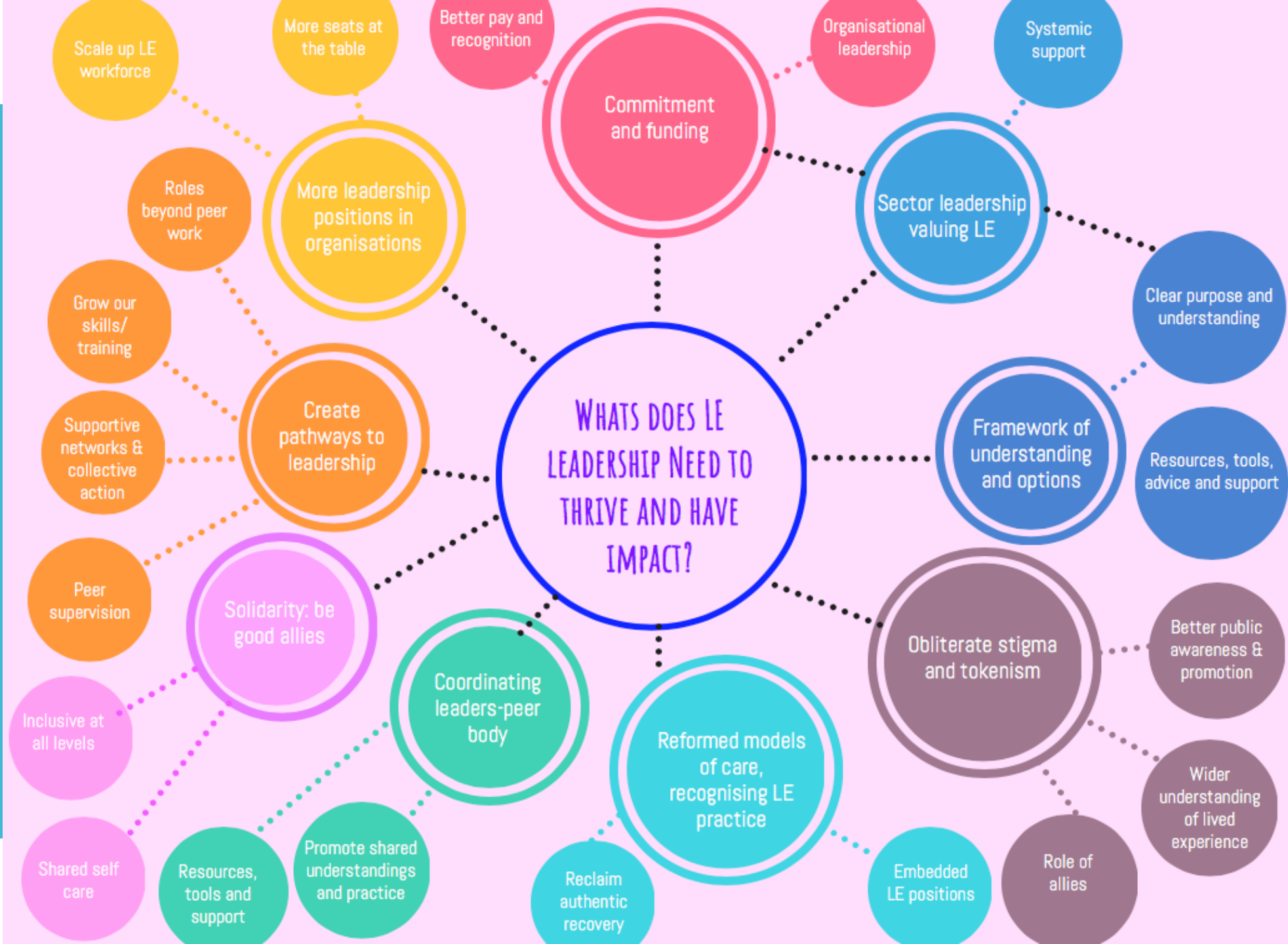












What we have been Noticing



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



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
- There are a range of strategies which are favoured for strengthening leadership capacity across the movement, within organisations and at the systems level
- 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. Where there is awareness there is limited knowledge how to apply, support, develop or embed it
- 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
- 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 them (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 phase two for the project to support the above



please send your comments and insights or
any questions you have to
Heather.McIntyre@unisa.edu.au by Friday
October 30th, 2020



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making contact
with us

