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A GROUNDED THEORY STUDY OF LIVED EXPERIENCE MENTAL HEALTH PRACTITIONERS WITHIN THE WIDER WORKFORCE

PLAIN ENGLISH SUMMARY AND RECOMMENDATIONS

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FOCUS OF THE RESEARCH

Lived experience practitioners (LEP) include all roles in the mental health sector that are specifically employed to work from their lived experience of significant mental health challenges, service use and Recovery. Some examples of LEP roles include; consumer companions, consumer representatives, peer support workers, experts by experience and lived experience academics.¹

The focus of the interviews was on factors that assist and inhibit LEP roles. Participants from diverse roles within government, non-government and lived experience-run services from metropolitan, regional and rural settings across several states and in a range of positions were interviewed to ensure a range of perspectives were represented.²

¹ For a justification of the term 'lived experience practitioner' please refer to chapter 2 of the thesis, under the heading 'Defining the lived experience workforce'.

² For details of recruitment please refer to Chapter 3 of the thesis, under the heading 'Data Collection'. For details of the demographic, please refer to Chapter 4 under the heading 'Participant Demographic'.

BACKGROUND

For over two decades mental health policy in Australia has insisted on a sector wide commitment to enhancing consumer participation and to promote the Recovery approach in mental health service delivery. However, this remains a work in progress with confusion over what Recovery concepts really are; how to work from a Recovery perspective and how to include consumers meaningfully.³

FINDINGS OF THE RESEARCH

This research found that effective roles for LEP are crucial to the success of mental health reform; embedding Recovery principles in the sector and meaningful inclusion of consumer participation.⁴ However, the emergent lived experience workforce in Australia currently faces a vast range of barriers.⁵

Common barriers across the diverse LEP roles inhibited current effectiveness and the future potential of roles. Barriers included a lack of formal employment structures and awards, lack of underpinning LEP devised theory and training, professional defensiveness or non-acceptance from non-lived experience colleagues and stigma and discrimination in the workplace.

A key finding of the research was that stigma and discrimination towards people with mental health challenges impacted on the role in obvious and less obvious ways. At times the influence of stigma was so subtle or so much a part of the 'normal' work experience it effectively became unseen. The term 'unseen stigma' used within this study also refers to the fact LEP roles are emerging within a culture that is often unknowingly or unconsciously stigmatising towards people with mental health difficulties⁶. Due to the unique qualification of LEP roles, this creates a fundamental challenge for individual LEPs within their daily work experience. Particularly in more traditional service settings where the dominance of the 'medical

³ For details of this please refer to the thesis Chapter 2 and, Chapter 5 under the heading 'Inhibiting Factors'.

⁴ Please refer to the thesis Chapters 2 and 5 for details and evidence of this.

⁵ Please refer to Chapters 4 and 5 of the thesis for details.

⁶ Stigma, seen and unseen is addressed within the thesis in Chapter 4 under the heading 'Unseen Stigma Defined' and Chapter 5 under the heading 'Stigma both seen and Unseen'.

model' directly inhibits Recovery focus and the effectiveness of LEP roles.⁷

Overall, the prevalence of barriers, including stigma (both seen and unseen) was so profound that to continue to be effective within the roles and to promote opportunities for future growth and evolution, participants regularly and knowingly risked their own well-being and Recovery and made significant personal sacrifices.⁸

Despite the barriers, the LEP workforce is promoting beneficial outcomes for consumers and assisting in much needed mental health reform. For best practice outcomes to be realised without compromising the wellbeing of LEP, LEP need to be supported in their roles with adequate workforce development, Recovery-focused work environments, acceptance and collaboration by colleagues and reduced or eliminated stigma and discrimination. This will first require an identification of stigma that is presently 'unseen'.

THEORY AND DIAGRAM

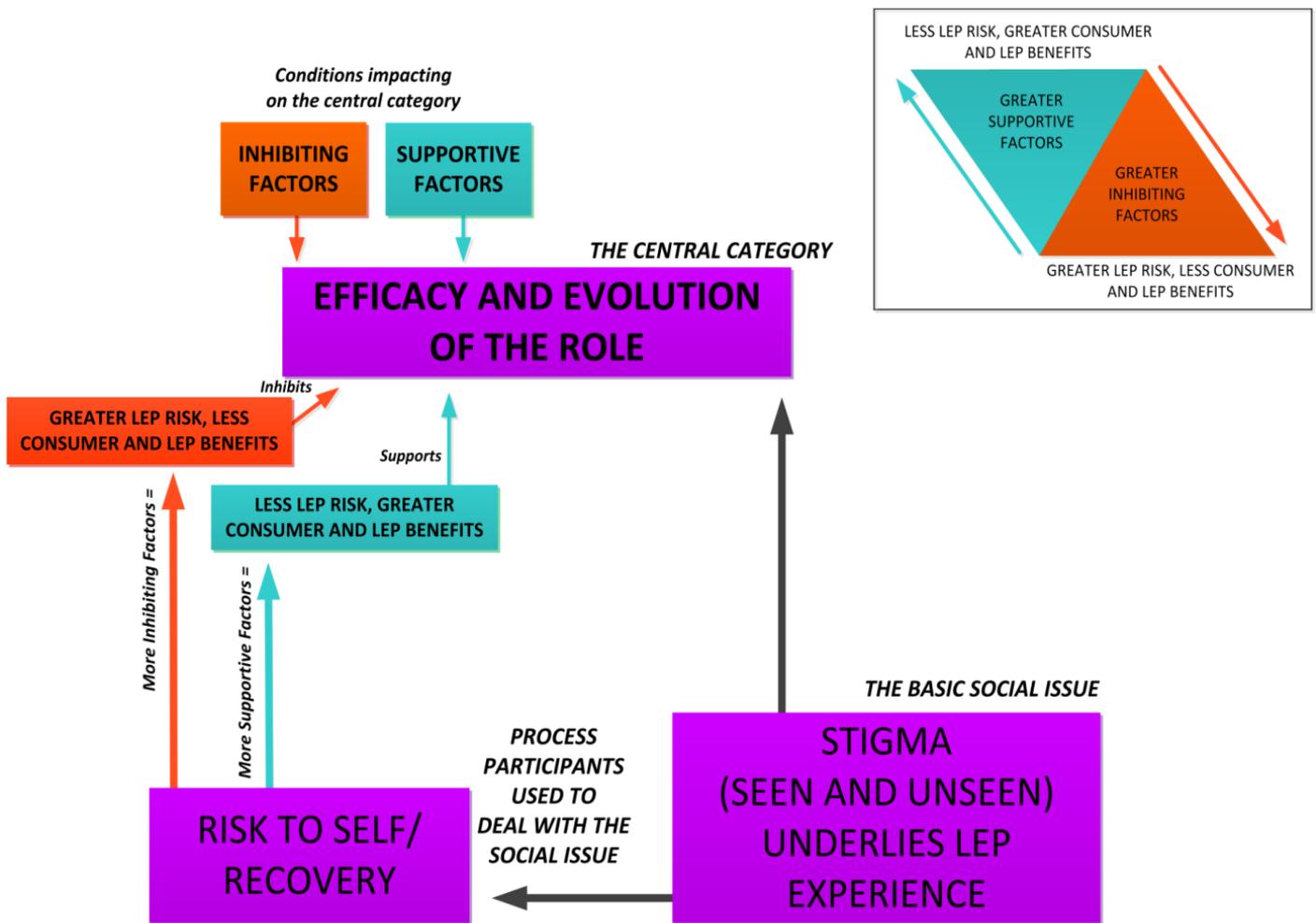
The 'central category' describes the core issue facing participants, in this study, the efficacy and evolution of LEP roles. Conditions impacting on the core issue were; supportive factors, inhibiting factors and stigma (seen and unseen). As a result of the stigma both seen and unseen, participants risked their own well-being and recovery. The study found that when workplaces were perceived as having more supportive factors, were more Recovery focused with less stigma and discrimination, there was a lower risk to LEP well-being, the LEP roles were more effective and there were greater consumer benefits. On the other hand, when more inhibiting factors existed, the medical model was dominant and more stigma and discrimination were present, greater risk to LEP was posed, the roles were less effective and less consumer benefits occurred⁹ (see figure 1).

⁷ For more on this refer to Chapter 5 of the thesis under the heading 'Medical Model'.

⁸ Refer to the thesis Chapter 4 'Risk to Self/Recovery' and Chapter 5 'Risk to Self and Recovery' for details.

⁹ For more on the substantive theory and more detailed diagrams refer to Chapter 5 of the thesis.

Figure 1: Substantive Theory diagram



CONCLUSION

LEP are the logical leaders of meaningful Recovery implementation and consumer participation and play a crucial role in essential mental health reform. However, for lived experience roles to evolve into full potentiality to the benefit of mental health consumers and LEP themselves, the underlying stigma that is often 'unseen' must first be recognised and addressed, negative risks minimised and supportive factors enhanced.

The following section provides the recommendations of the study to provide further direction on how to progress the evolution and effectiveness of LEP roles and promote supportive factors.

RECOMMENDATIONS

The recommendations section contains several sets of recommendations relating to or specifically directed at;

- Employers of LEP
- The LEP movement including Peak Bodies
- Policy Makers and Governing Bodies
- Research
- Education

BEST PRACTICE FRAMEWORK FOR EMPLOYING LEP

- **Planning and Preparation:** Considerable time and effort is given to consultation with LEP leaders and groups to inform the development of positions, position descriptions and the change management practices and infrastructure required. Current roles for LEP are reconsidered and in some cases redesigned - informed by research, best practice and potential future expansion.
- **Start at the Top:** Management understand the principles, language and background of LEP work and the benefits to services, including the ability of LEP to provide leadership in Recovery practice. This valuing of LEP roles also translates into appropriate remuneration, work space and resources and access to LEP training delivered by other LEP. Affirmative action is employed to ensure LEP perspectives are incorporated at all levels of service delivery.
- **Filters Down:** Management meaningfully communicates their in-depth understanding of LEP value, practice and potential to senior team members and team leaders. An organisational commitment to the principles of LEP leadership in Recovery and to meaningful collaboration between LEP and non-LEP within the workplace is clearly articulated and expected.

- **Whole of Workplace Approach:** The culture of the workplace itself must be inclusive and Recovery focused or at least willing to be. Senior team members and leaders effectively communicate the same information to all team members to ensure LEP is valued within all levels of the organisation and LEP roles are meaningfully involved and enabled to take leadership regarding Recovery orientation.
- **Employ the right person for the right job:** Position descriptions are created in conjunction with LEP leaders and groups before beginning the process of recruitment to ensure the role is meaningful and impactful. All roles have appropriate wages, comparable to non LEP positions and provide career pathways. Full-time roles are developed as well as part-time positions. For systemic or senior roles particularly, positions are substantive enough to attract the most qualified people.
- **Reasonable accommodations:** In conjunction with LEP leaders and groups, flexible work arrangements are considered in relation to how the culture of the workplace can be modified to create an inclusive environment for the benefit of all staff.
- **Discussion Encouraged:** Discussion and respectful debate is encouraged to allow non LEP to explore and understand the roles and LEP to provide their perspective to the dominant, pre-existing culture.
- **Uniqueness is Preserved:** LEP are enabled to work from their unique perspective in ways that are informed by the consumer movement, LEP literature and is appropriate to them as individuals. There is no coercion for LEP to mimic other service roles.
- **Ongoing Commitment:** The existing paradigm won't change quickly or with one big push. A commitment is therefore made and actioned to provide periodic or ongoing attention to workplace culture.

RECOMMENDATIONS FOR LEP MOVEMENT, PEAK BODIES

- **Collaborate meaningfully with LEP leaders**, both well recognised and lesser known who are providing innovative ideas and approaches to ensure the 'voice' provided is the best informed and represents contemporary best practice.
- **Create networking opportunities** to encourage membership of the movement and an online space for LEP all over Australia to be aware of what is happening in other areas, particularly to allow those in rural and regional areas to feel connected.
- **Communicate the findings of LEP research** and other important thinking to relevant government and governing bodies.
- **Advocate for LEP leadership of Recovery concepts** and Recovery-orientated practice across the sector and in the training, education and employment of other LEP.
- **Encourage multiple ways of doing** and working together to reduce infighting and be as united as possible. Lead by example.

RECOMMENDATIONS FOR POLICY MAKERS AND GOVERNING BODIES

- **Address stigma and discrimination of LEP** as an issue with legal ramifications, contravening the Fair Work Act and other similar State Acts. Ensure that policy clearly articulates and enforces zero tolerance for stigma and discrimination for all workers, including LEP.
- **Lived experience led Recovery concepts are differentiated from the existing, confused concept** many clinicians have about Recovery and LEP are acknowledged as logical leaders in the on-going implementation of the Recovery approach. LEP are proactively enabled to provide leadership in all arenas pertaining to Recovery including education, policy, service design and national frameworks.
- **Create more senior positions for LEP** in a range of settings to allow this leadership to have impact and authority. Affirmative action is employed to ensure greater inclusion of LEP perspectives

within governing bodies and upper level management and insisted upon within funding arrangements and policies.

- **With significant LEP involvement, explore a more evidence-based, Recovery oriented approach than the DSM - V** to assist people to understand their experiences with mental health difficulty in more person-centred and Recovery promoting ways and to challenge the continuing dominance of the medical model.
- **Informed by research, the LEP movement and best practice, consider the potential scope of LEP roles both within and beyond the mental health sector.** Examine the design of current roles in conjunction with the LEP movement and relevant research to promote greatest efficacy and future evolution.
- **Significant financial investment in the provision of wide scale LEP devised and delivered Recovery education** for the existing mental health workforce and to encourage Recovery education in educational institutions.
- **Provide greater funding to increase the hours of existing positions,** create more positions in metropolitan and rural and regional areas and subsequently reduce the burden of additional unpaid work on current LEP and increase benefits to consumers.
- **Commission research into the needs of rural and regional communities and the role LEP may play** in addressing the inequity between metropolitan and rural and regional districts.

RECOMMENDATIONS FOR FUTURE RESEARCH

The following recommendations should all be LEP led

- Explore the benefits of mental health ‘difference’ – the gift in the curse and how a different way of viewing mental health challenges might impact on outcomes for consumers.

- Explore alternate, Recovery appropriate means of describing mental health challenges than the existing DSM - V classification system.
- Continue to explore the impact of LEP on recovery outcomes for consumers, with a particular focus on how the efficacy and evolution of the LEP role impacts on benefits to consumers. Include examination of different service settings to establish which allow for the greatest consumer benefits and consideration of how broadening the scope of LEP practice could impact on benefits to consumers.
- Explore the unique needs of rural and regional communities in relation to the potential roles LEP may play in addressing the inequity between metropolitan and rural and regional districts.
- Explore the development of Indigenous LEP positions with attention to current barriers, including the need for culturally appropriate language and concepts of mental health. Create research that jointly examines the lived experience benefits of Indigenous cultural roles broadly and mental health lived experience roles.
- Explore the extent to which mental health clinicians are engaged with the concept of Recovery.
- Continue research into the efficacy of LEP led Recovery concepts and how they should be applied within services and the wider structure.
- Explore the degree to which Recovery uptake in an organisation supports or inhibits the success of LEP roles. Include consideration of the degree to which different service settings; government, non-government and LEP-run, have embraced Recovery concepts, learn what is working and where change is required. Further consider the current and potential scope of LEP practice and how workplace culture impacts on the ability for potential to be realised.
- Explore how membership of the consumer movement impacts on LEP and how to encourage unity within the movement.
- Conduct research into the efficacy of both lived experience and non lived experience supervision of LEP to establish best practice models.

- Explore the role of LEP management of LEP and the impact that has on risk, sacrifice and job satisfaction for LEP as well as benefits for consumers.
- Examine the degree to which 'support in numbers' – LEP not being professionally isolated, impacts on positive outcomes for LEP and consequently benefits to consumers.
- Explore the experience and impact on LEP of disclosing their lived experience.
- Compare and contrast the experiences of people who have a lived experience of mental health challenges and work within the mental health system in more traditional – non-LEP roles with those of LEP.
- Define LEP theory and language, including what is meant by 'lived experience' and ensure collective LEP ownership of these concepts. Explore what is needed to create comprehensive and role specific LEP training that protects the integrity and uniqueness of the roles.

RECOMMENDATIONS FOR EDUCATION AND TRAINING

The following recommendations should all be LEP led

- Deliver widely accessible LEP training inclusive of the collectively defined theory and language of lived experience practice. Training will be government funded or paid for by employers to address the urgent need for capacity building and appropriate training required in a range of service and educational settings. Training for LEP will differ depending on the specific role or area of focus, the needs of disparate roles will also need to be carefully considered in the design.
- Design and deliver Recovery education for all mental health workers across the sector with follow up or ongoing refresher training to allow for the immense cultural and philosophical changes required to move from a medical model to the Recovery approach in mental health. This training should be designed and delivered by LEP and assist existing workers to understand the benefits of Recovery to their practice, particularly in relation to consumer benefits. The training should also

differentiate between consumer-led Recovery and co-opted interpretations, enabling more meaningful Recovery engagement.

- Recovery education as a fundamental component of all mental health education, including VET and tertiary, across all disciplines. This education should be lived experience led and include clarification on the consumer-devised Recovery concept in contrast to co-opted interpretations. Students should also learn skills to advocate for Recovery and be prepared to act as champions and change agents within the wider sector.