

Summary:

Identifying barriers to change: The lived experience worker as a valued member of the mental health team

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Acknowledgments

We wish to pay respect to Aboriginal and Torres Strait Islander Elders, past and present, and acknowledge the important role of Aboriginal and Torres Strait Islander people, their culture and customs.

We acknowledge people with a lived experience of mental health and drug and alcohol challenges, their families and significant others. We stand in solidarity, with hope that anyone may go on to live a purposeful and meaningful life of their own choosing.

We give particular acknowledgment to our pioneering brothers and sisters in the consumer/lived experience movement who paved the way for the possibilities that exist today.

This project was funded by the Queensland Mental Health Commission. All the researchers working on the project identify as having a lived experience of significant mental health challenges, service use and periods of healing, and primarily work within lived experience roles.

Byrne, L. Roennfeldt, H. and O'Shea, P. *Identifying barriers to change: The lived experience worker as a valued member of the mental health team: Summary*. Brisbane: Queensland Government; 2017.

For greater detail please refer to the full report:

Byrne, L. Roennfeldt, H. and O'Shea, P. *Identifying barriers to change: The lived experience worker as a valued member of the mental health team: Final Report*. Brisbane: Queensland Government; 2017.

Executive summary

The lived experience workforce in Australia includes peer support workers; consumer consultants; consumer companions; experts by experience and various lived experience roles in education, training, policy design and systemic advocacy. This emergent and increasingly impactful section of the mental health workforce is growing rapidly, however expansion of the roles is ad hoc with little structured workforce development to date. Previous research also indicates the way lived experience workers are collaborated with, integrated or utilised is highly variable.

A Grounded Theory study funded by the Queensland Mental Health Commission explored executive/senior management perspectives on the barriers and enablers facing the lived experience workforce, with a particular emphasis on why organisations were embracing lived experience workers to greater or lesser degrees. In-depth interviews and focus groups were held with 29 participants in total; 16 participants employed within the not-for-profit sector, 13 employed in state government run organisations.

*Executive/senior management commitment and action
is critical to the success of lived experience roles*

The findings of the study overwhelmingly indicate executive/senior management commitment and action is critical to the success of lived experience roles. Greater or lesser understanding of lived experience work and perceived value by executive/senior management proportionately impacted the degree of commitment and action demonstrated by management. Subsequently, the degree of management commitment influenced organisational factors and ultimately, the evolution and future growth of lived experience both within organisations and outside the mental health sector.

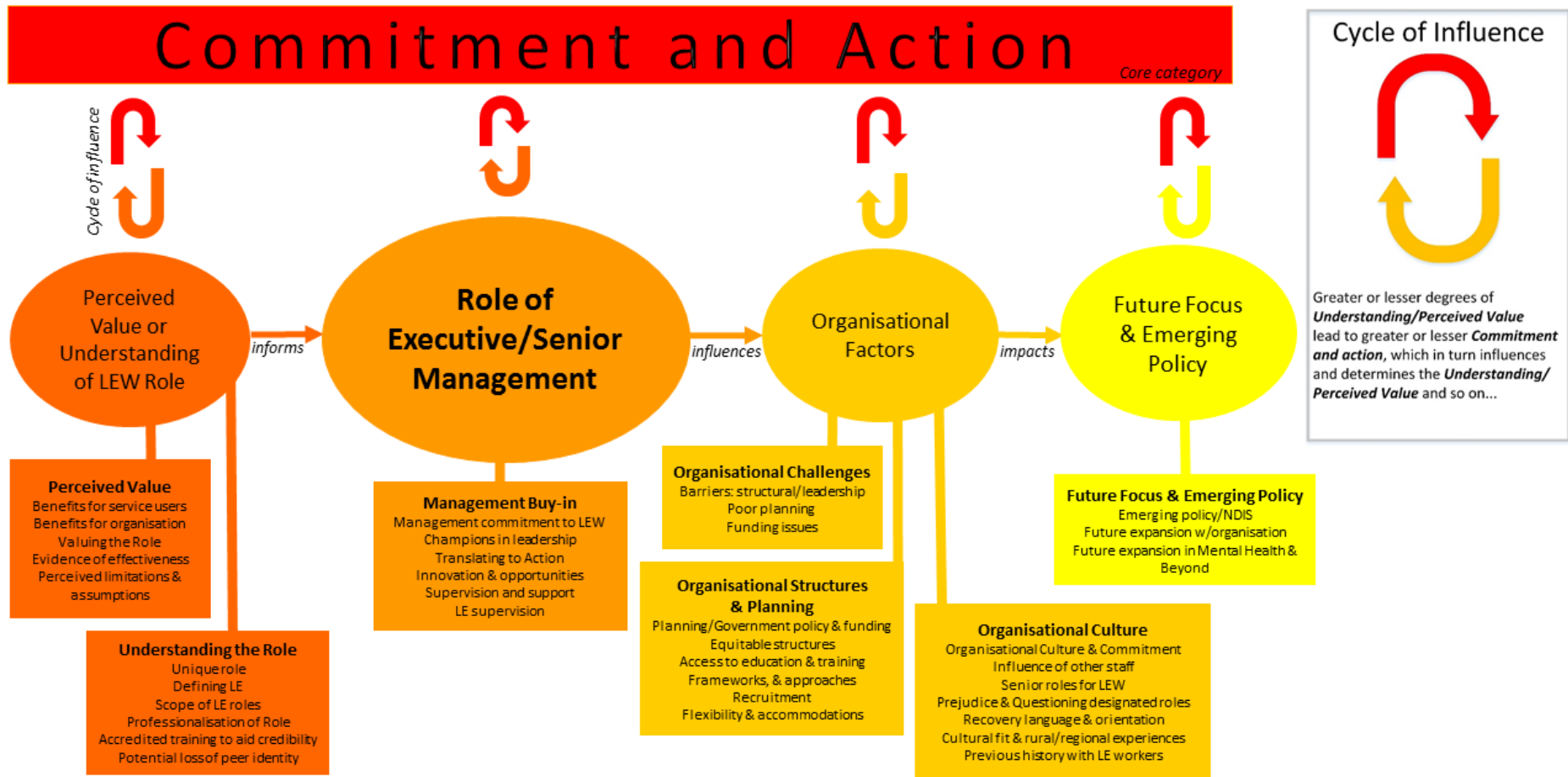
Key findings

The core category emerging in this study was *commitment and action*. 'Commitment and action' in this context refers to instances or situations where commitment and action is, and is not demonstrated.

The degree to which executive/senior management value and understand lived experience roles, directly correlates to the commitment shown in developing and supporting lived experience workforce within organisations

The theory derived from this study shows that, *the degree to which executive/senior management value and understand lived experience roles, directly correlates to the commitment shown in developing and supporting lived experience workforce within organisations*. The degree of commitment and action demonstrated by executive/senior management was also shown to proportionately affect the potential for future growth and opportunities for lived experience roles.

This diagram demonstrates the core category – commitment and action, all the major categories and the sub-categories and concepts that related to each category. The diagram provides a one-page summary of all the key findings.



“Defining barriers to change: the LEW as a valued member of the team”

Discussion summary – key points

Leadership role for executive/senior management

- Executive/senior management provided crucial leadership in the development of lived experience roles.
- Personal and organisational commitment to the lived experience workforce increased with greater investment and greater clarity on the benefits of lived experience work.
- Risks and efforts in developing the lived experience workforce were seen to be worthwhile.
- The overarching message from those who have made a commitment to lived experience workforce development was 'just do it'.

Speculation versus experience

- The more experience/exposure participants had to lived experience roles the more highly the roles were understood and valued.
- Greater exposure also engendered greater confidence in the resilience and capacity of lived experience workers.

Previous negative experiences with lived experience roles

- Negative experiences with previous lived experience workers were often seen to be the result of flawed recruitment process and/or poor role clarity.
- Organisations with significant experience employing lived experience workers described changes to recruitment processes as understanding of the roles grew.

Value of role: benefits of lived experience roles

- Many positive effects of lived experience work were identified by participants. These benefits were seen to extend to: the organisation, colleagues in traditional roles and service users.
- Lived experience workers were seen to promote and provide: empathy, hope, equality, trust, mutuality, connection, understanding and education.

- Lived experience workers were also seen to contribute significantly to positive workplace culture, particularly in improving recovery orientation and reducing prejudicial attitudes.

Understanding and supporting the uniqueness of lived experience

- Lack of understanding or clarity about lived experience created risks for lived experience roles in being absorbed and co-opted into traditional ways of working, diminishing their impact.
- When the uniqueness of the roles was understood it was actively protected and reinforced.

From fear to understanding

- Simply by being there in designated roles, lived experience workers challenged prejudicial attitudes towards people with a lived experience, including service users.
- As a result of lived experience employment, fear and negative assumptions about people with a lived experience were reduced, resulting in greater understanding and empathy.

Champions

- Champions were seen to be willing to share power with lived experience and actively advocated for and promoted lived experience roles.
- Champions were invaluable in campaigning for lived experience positions that allowed more meaningful and equal input.

Senior roles for lived experience

- The inclusion of lived experience executive/senior management roles was seen to provide unique opportunities for cultural and organisational change.
- Lived experience executive/senior management roles had great potential impact due to their position in the organisation and presence at governance and other key meetings.

Frameworks and professionalisation of the roles

- While some guidelines or structure are necessary for accountability and credibility, greater flexibility for lived experience roles was seen to support service user driven recovery.
- Professionalisation for the lived experience workforce is viewed as a 'double-edged sword' with potential for higher credibility and status on one hand, but also an increased risk of being co-opted into less flexible, traditional ways of working.
- The development and/or greater availability of lived experience specific training and skill development, based on agreed upon theoretical underpinnings, is seen as desirable.

Reasonable accommodations

- Significant variety was found in the way reasonable accommodations were viewed.
- The majority with experience managing a lived experience workforce favoured flexibility in roles and saw flexibility as relevant to both lived experience and staff in traditional.

Whole-of-service approach

- The need for a whole of service approach was identified, including workplace culture, policies, equitable structures, access to training and education, and support and flexibility.
- Equitable structures aided the success of lived experience roles and included career pathways and access to training.
- Addressing workplace culture was seen as essential in preparing the organisation for lived experience roles.
- The important role of supervision and support was acknowledged in maximising the success of the lived experience workforce.

Recommendations summary

Several recommendations arose from the research. The recommendations centred on providing opportunities to increase understanding of the uniqueness of lived experience roles. Opportunities for exposure to lived experience work were also highly prioritised as it was seen to increase the perceived value of the roles.

Recommended platforms suggested to aid understanding include;

- education and training
- developing relationships with organisations who had a more developed lived experience workforce
- the employment of lived experience workers in senior roles.

The recommendations also addressed the integral role of executive/senior managers in leading a whole of organisation approach. Several factors were emphasised including the need for;

- investment
- commitment
- innovation
- 'champions'
- sufficient planning
- time.

Addressing role clarity, support and supervision and, equitable structures were also recommended as important factors. Attention to these factors was seen to maximise the successful development of lived experience workforce.