Final Report:

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.

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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 overwhelming 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.

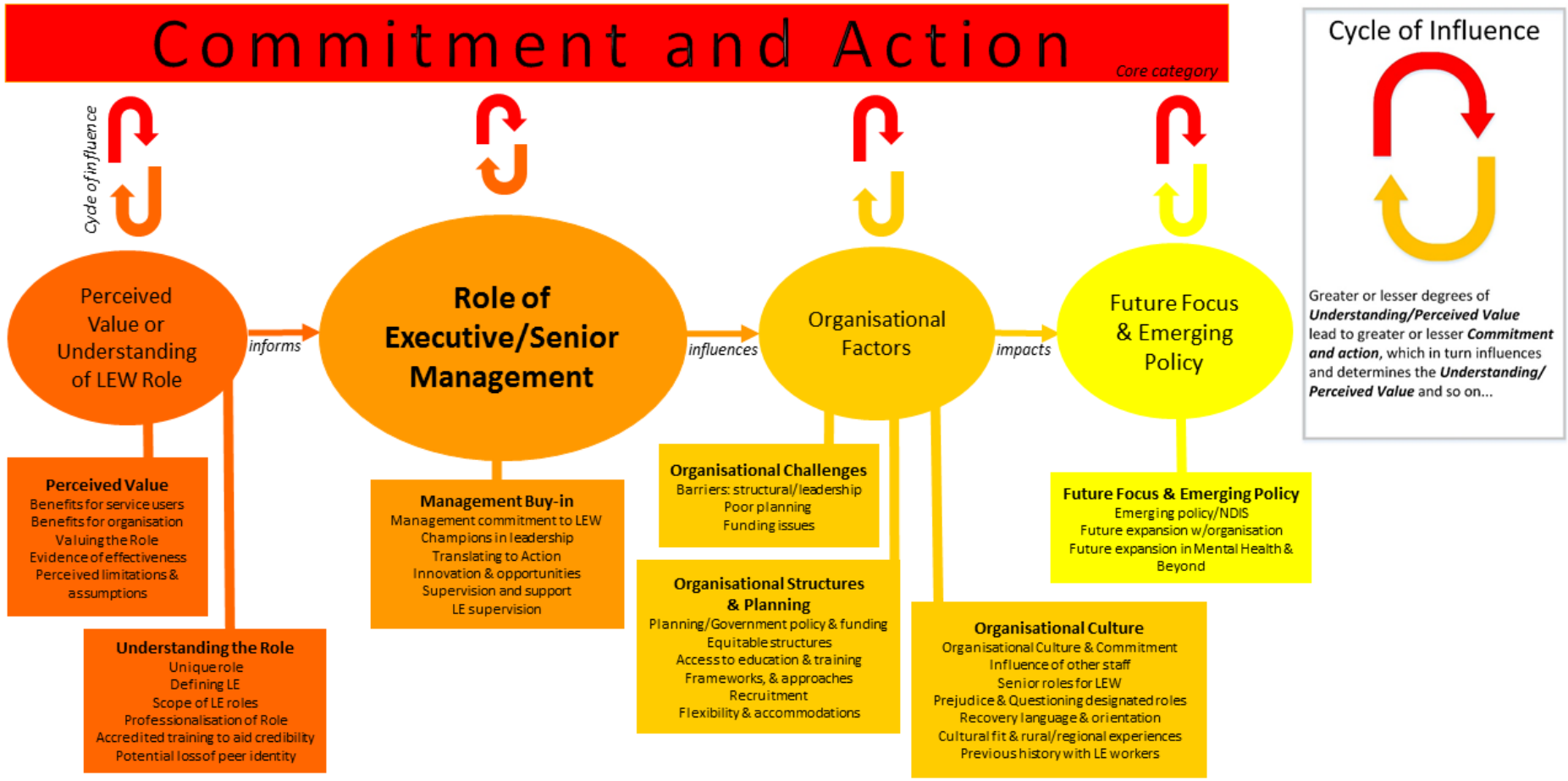
Key findings

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.

Introduction

Lived experience workers have experienced mental illness, recovered and learned to use their 'lived' understanding of mental health challenges to assist others [1]. Employment of lived experience workers (LEW) can significantly reduce costs for mental health services [2] and improve outcomes for people with mental illness [3]. However, not all mental health professionals currently accept the role of LEW within the mental health workforce [4].

One of the greatest identified barriers to lived experience work in the mental health sector is the attitudes of some mental health professionals, including professional defensiveness and a lack of collaboration or engagement [5]. In addition to issues of professional defensiveness, some mental health professionals are sceptical about the value of LEW [6] and many LEW face stigma and discrimination within their roles [7], suggesting targeted work needs to be done to address these attitudes.

For lived experience workers within mental health settings to reach full potential, they must be meaningfully integrated within the larger workforce and senior management attitudes are a critical element of ensuring this integration [8]. Having senior management within a service that are supportive of lived experience workers has been identified as a crucial supportive factor [9]. Personal beliefs and attitudes of senior managers have been found to 'trickle down' in a variety of ways and influence the acceptance and perceived value of LEW within the workplace [10].

Research design

Aim

Understand the perspectives of senior managers of mental health services regarding the barriers and enablers for lived experience workers within the mental health sector.

Research methods

Grounded theory as an approach is well suited to areas where little is known about an issue[11], as with senior managers' perspectives of the barriers and enablers for LEW.

The research was based in Queensland and participants were invited from a range of government and non-government organisations across the state. Utilising existing networks, rural and regional perspectives were sought as well as metropolitan.

Ethics

Ethical approval was received from CQUniversity (H15/11-262), and Queensland Health (HREC/16/QPCH/298). Site Specific Applications were consequently submitted to seven Queensland Health, Hospital and Health Services (HHS) and approval was gained from all. Six of the seven HHS also required research contracts/agreements to be developed and signed by legal teams at CQUniversity and the respective HHS. As each HHS had a slightly different process for the site specific applications, some HHS approval processes took longer than others. One of the seven HHS was not able to be included in the study as approval arrived after data collection and analysis has ceased.

Recruitment

Participant recruitment

A database was compiled by the research team, of persons in relevant roles within government and non-government mental health services in Queensland. This database was then used to identify potential organisations and participants.

Participants were also recruited through relevant State networks including the Qld Voice (peak body for consumers in Queensland), Qld Alliance (peak body for non-government mental health organisations) and Queensland Health (government mental health organisations).

Chief Executive Officer approval

Before any invites to participate were sent, the Chief Executive Officer (CEO)/Executive Director of relevant organisations were contacted and asked to provide written permission for their staff to participate. Forty-nine (49) CEO letters were sent and 24 CEO approvals were received. If any CEO or Executive Director did not provide consent, employees of their organisation were not approached. A copy of the CEO letter template is included in the Appendix.

Invite to participate

Once CEO approval was gained, an email was sent through the networks and to individuals identified in the database, explaining the aim and design of the project and inviting interested persons to contact the Principal Investigator. A copy of the email to participate is included in the Appendix.

Emails sent to individuals identified within the database were individually addressed and sent directly to their work email address, provided by the contact staff member for the CEO approval letter.

Additionally, general emails – not individually addressed were sent through networks and to consenting organisations for distribution on staff email lists. This allowed potential participants to self-select.

Included in the email was a brief description of the research project. Attached to the email were additional forms, copies of the email and all forms are included in the Appendix. The Information Sheet, and information on the consent form itself, made clear that interviews conducted would be video or audio recorded. A short demographic questionnaire was also sent. The demographic asked potential participants to indicate the following information for sampling purposes:

1. Name
2. Role within the organisation
2. Does your organisation employ lived experience workers
3. Are you or have you ever been responsible for the supervision of lived experience workers
4. If yes, how many and what role/s do they hold within the organisation

Additionally, the demographic asked potential participants to identify if they were willing to participate in either a focus group or interview, or interview only.

Potential participants were informed that a member of the research team would contact them via phone or email if they choose to participate in either the focus group or interviews. They were asked to send an email to the contact researcher if they would like any further information regarding the study prior to participation. The CQUniversity team then phoned and/or emailed each potential participant to discuss the study further and make a time for interview or confirm attendance at the focus group.

Informed consent

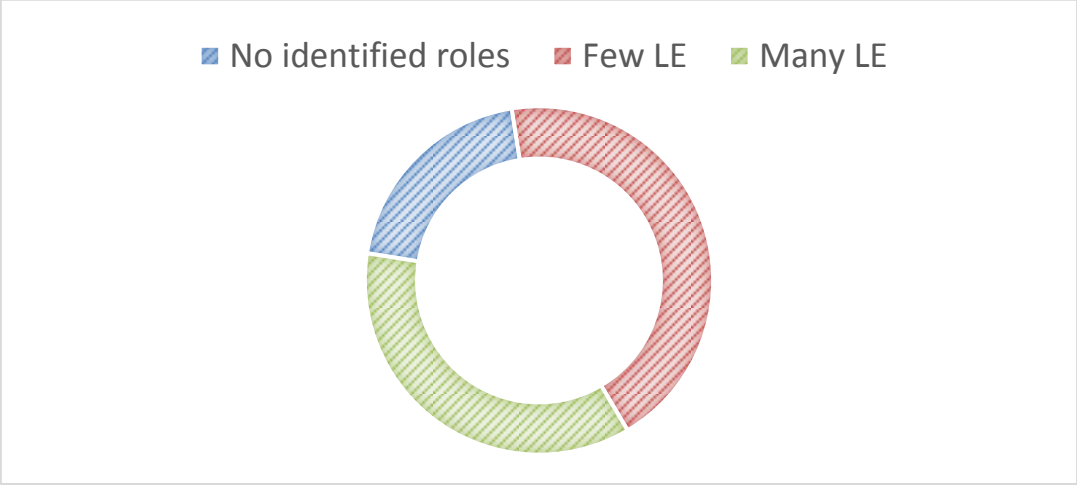
All participation was entirely voluntary. All consent was informed, with information on the research process provided in 'everyday people' language. Participants were free to withdraw without penalty at any stage of the process.

Confidentiality

Participants were also assured participation would be strictly confidential and confidentiality would be ensured by removing any identifying information including, names, place names and other unique data, before analysis began. After transcription, pseudonyms were assigned to participants and others named within the transcripts. Due to the relatively small amount of designated lived experience or carer executive/senior management roles, gender was also disguised by randomly allocating traditionally male or female names regardless of the participant's gender.

Organisation/service names, towns, cities, districts and other identifying information were also coded. Work places were coded by the number of lived experience workers within the organisation, i.e.: Many LE, Few LE, no identified roles. Some organisations had very large numbers of overall staff and others were much smaller, making this a difficult categorisation, but as a general guide set numbers were decided upon to indicate the degree of lived experience employment.

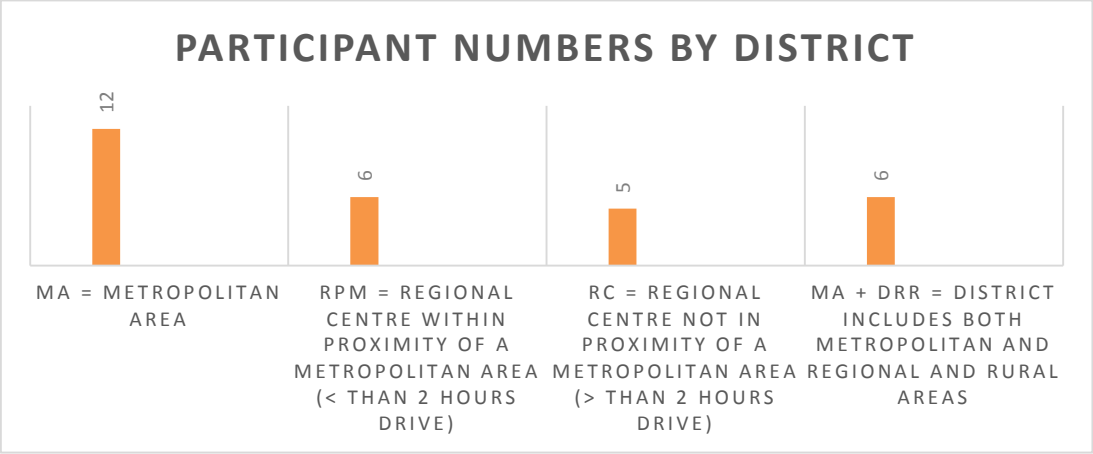
Figure 1: Number of lived experience roles in organisations



'Many LE' indicated the current employment of 6 or more designated lived experience roles within the organisation. 'Few LE' indicated the current employment of 5 or less lived experience workers. 'No identified roles' indicated there were currently no lived experience workers employed. As stated, organisations were of varying sizes so this categorisation provides a very loose guideline but does provide some indication of the degree of exposure different organisations had to lived experience roles.

Towns or districts were also coded according to the type of region; MA indicating a metropolitan area; RPM, a regional centre within proximity of a metropolitan area (approx. less than 2 hours drive); RC indicated a regional centre not in proximity of a metropolitan area (approx. more than 2 hours drive); DRR, were districts that included both regional and rural areas. On a few occasions the services or organisations covered large areas containing Metropolitan, regional and rural areas which was represented as MA + DRR. Figure 2 demonstrates the distribution of participants across district types.

Figure 2: Participants by district type



Secure storage

All data was and will continue to be stored in locked files throughout the duration of the research and for a period of five years following completion of the last publication based on the data. Coded transcripts are stored separately to identified material.

Participant sampling

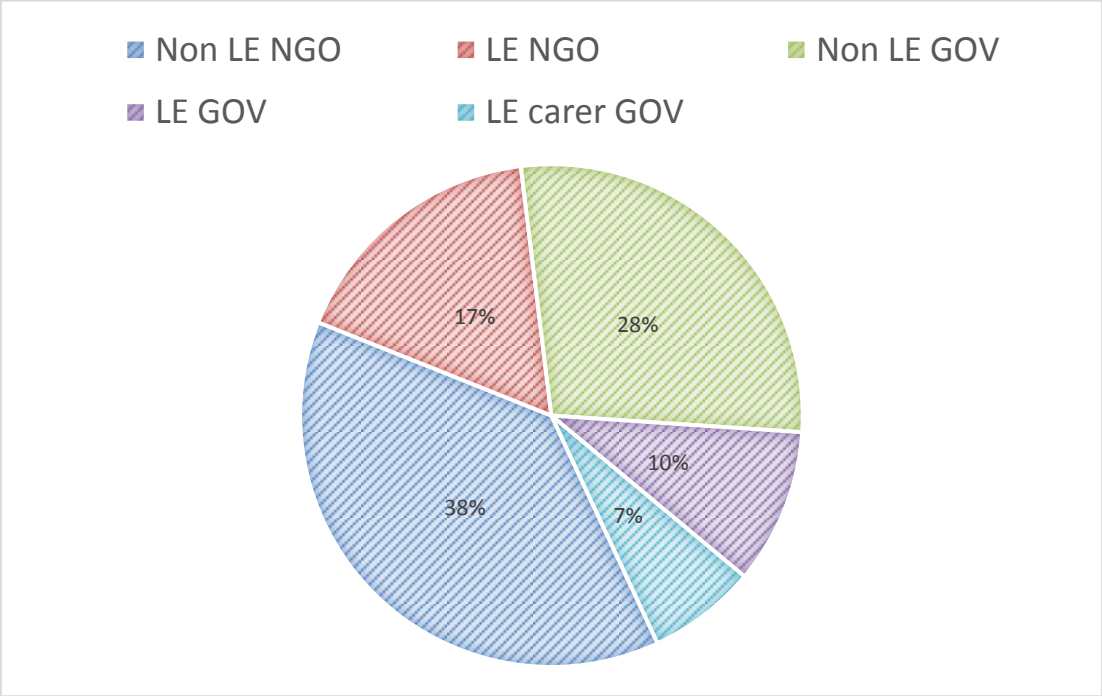
Participants were purposively sampled, focusing on people employed within executive and senior management roles. For the purposes of this study the definition of executive/senior management included: executive level staff, people with responsibility for allocation of staffing budgets, the ability to hire and fire, and those with line management/supervisory responsibilities for lived experience staff.

In line with grounded theory, initial data collection included a broad sample of participants from a range of organisations with greater and lesser degrees of employment of lived experience staff. As data collection and analysis progressed, participant were selected according to their ability to expand on concepts emerging from the data. This process of selecting participants based on the emerging issues is a standard approach in Grounded Theory referred to as theoretical sampling[12], and was re-enacted throughout data collection. The short demographic questionnaire attached to the initial email assisted the appropriate selection of participants. This demographic aided selection of the next most suitable interviewee, determined by their experience (or lack thereof) in the employment and management of LE workers. A copy of the demographic is attached. Consideration was also given to including a variety of perspectives from state government run facilities and non-government/not-for-profit organisations.

Data collection

In-depth, semi-structured interviews and focus groups were held with a total of 29 participants. 16 participants were employed within the not-for-profit sector and 13 were employed in state government run organisations. 25 in-depth interviews were conducted and one focus group. Six people attended the focus group and one focus group participant also chose to be interviewed. Participants were predominantly employed in traditional roles, however some participants identified as working within designated senior lived experience positions. Figure 3 demonstrates the distribution of lived experience and traditional senior roles across organisational types.

Figure 3: Participants by role and organisation type



Non LE NGO indicates participants in traditional executive or senior management roles within non-government/not-for-profit organisations.

LE NGO indicates participants in designated lived experience executive or senior management roles within non-government/not-for-profit organisations.

Non LE GOV indicates participants in traditional executive or senior management roles within government organisations.

LE GOV indicates participants in designated lived experience executive or senior management roles within government organisations.

LE carer GOV indicates participants in designated carer executive or senior management roles within government organisations.

Interviews

As in-depth interview was the first point of data collection, in line with grounded theory a broad range of perspectives was sought to allow identification of initial concepts/issues meaningful to the participants. These concepts were then used to guide the next phase of data collection and inform which participants would best provide further clarity on issues emerging within the interviews.

The aim of interviews was to identify the enablers and barriers to lived experience work as seen by senior managers. Guidance was also sought on how to successfully integrate lived experience roles. The interviews took approximately one hour.

Focus groups

A focus group was held to provide early verification of emerging concepts, a different forum of involvement and to add the discussion between peers and subsequent data that may arise from that process of discussion. The focus group included 6 participants. Due to time restrictions of participants, the focus group ran for 45 minutes.

Data analysis

Constant comparative analysis and evolving interview questions

In line with grounded theory, the researchers transcribed and analysed data throughout the research process to inform the questions for subsequent interviews/focus group and to aid theoretical sampling of participants [12]. Grounded theory doesn't assume knowledge by providing a theory to test, but rather allows the data to reveal the answers[13]. For this reason, interviews and focus group began with very broad questions. The first three questions of the focus group and interviews were consistent:

Q1. Could you please tell us about your perspective on the current employment of LE workers?

Q2. In your opinion what helps to successfully integrate LE roles within the wider workforce?

Q3. Can you think of any barriers to successful integration and what might be done to improve the situation?

As interviews progressed, in line with grounded theory, common themes raised by participants were explored[14]. Additional area of interest included;

- the professionalization of the lived experience workforce
- the idea lived experience workers are 'not that different' to other roles
- attracting and retaining lived experience workers
- burnout for lived experience workers

- the idea of how ‘recovered’ someone is affecting their ability to work
- the role of supervision
- stigma/discrimination
- defensiveness or perceived ‘threat’ to other roles due to the increase of lived experience roles
- differences in uptake of lived experience roles in more highly populated areas where competition between services drives innovation

Coding

The researchers used coding features within NVivo software but undertook manual analysis of the data. Several researchers conducted interviews and analysed the data, swapping and checking each other’s coded transcripts to enhance credibility. In addition, researchers employed memos as a strategy for identifying and separating bias.

Initially all transcripts were ‘open’ coded using line-by-line analysis to identify emerging concepts. As per grounded theory, at later stages of data collection and analysis, concepts were considered in relation to other emerging concepts and consequently clustered in sub-categories and categories according to their properties[12]. Finally, nearing the end of data collection, a central phenomenon or category was identified: the core category to which all categories and concepts relate [14].

Saturation and verification

Once saturation had been reached – the point at which no new concepts were emerging from the data [12], a total of four participants were asked to give feedback on the initial substantive theory. In this process, participants were given a copy of the initial substantive theory diagram and the emerging theory was discussed.

The goal of verification is to ensure the findings are grounded in the experiences of the participants and are viewed by participants to be an accurate representation of their experiences. To ensure the different demographics were represented, one participants was approached and provided verification from each of the following demographics:

- 1 Non LE NGO - a participant employed in a traditional executive or senior management role within a non-government/not-for-profit organisation
- 1 LE NGO - a participant in a designated lived experience executive or senior management role within non-government/not-for-profit organisation
- 1 Non LE GOV - a participant in a traditional executive or senior management role within a government organisation
- 1 LE GOV – a participant in a designated lived experience executive or senior management role within a government organisation

As with interviews, after consent was given verification sessions were recorded and transcribed. The participants were largely in agreeance with the findings. The first participant suggested the most changes, all of which were acted upon by the research team. In subsequent verification sessions participants proposed increasingly less changes. By the final verification the participant was entirely in agreeance with the theory and no further changes were proposed.

Findings in summary - theory and core categories

Core category

The core category emerging in this study was *commitment and action,* as all the categories and concepts of the study have clear relationship with and/or indicators pointing to this category [12]. As the findings demonstrate, the phrase 'commitment and action' explains both complementary and contradictory concepts within the study. That is, instances or situations where commitment and action is, and is not demonstrated. See also, *Diagram 1: Core category and other categories.*

Substantive theory/key findings

The theory derived from the findings of this study show 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.

> 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

Major categories

Perceived value or understanding of the lived experience role

When executive/senior management held a higher *perceived value or understanding of the lived experience role*, commitment and action in relation to lived experience workforce development consequently increased. Increases in the *commitment and action* in turn added to the *perceived value or understanding of the lived experience role.* Those

organisations who had made the greatest investment in lived experience work expressed the highest perceived value and intention to continue developing the lived experience workforce.

Role of executive/senior management and organisational factors

The degree of commitment demonstrated by the *role of executive/senior management* directly impacted on the time and effort that had gone into *organisational factors* including organisational challenges, structures and planning and workplace culture. Similarly, increased organisational commitment created a cycle of continued action in developing lived experience roles.

Future focus and emerging policy

Finally, *future focus and emerging policy* was seen to be a result of the degree of *commitment and action* shown by executive/senior management and consequently organisations. Greater perceived value, understanding and commitment to future lived experience workforce development was found in organisations who had invested in lived experience roles.

All categories and concepts are represented diagrammatically in *Diagram 2: Substantive theory diagram (all categories and concepts).*

Diagram 1: Core category and other categories

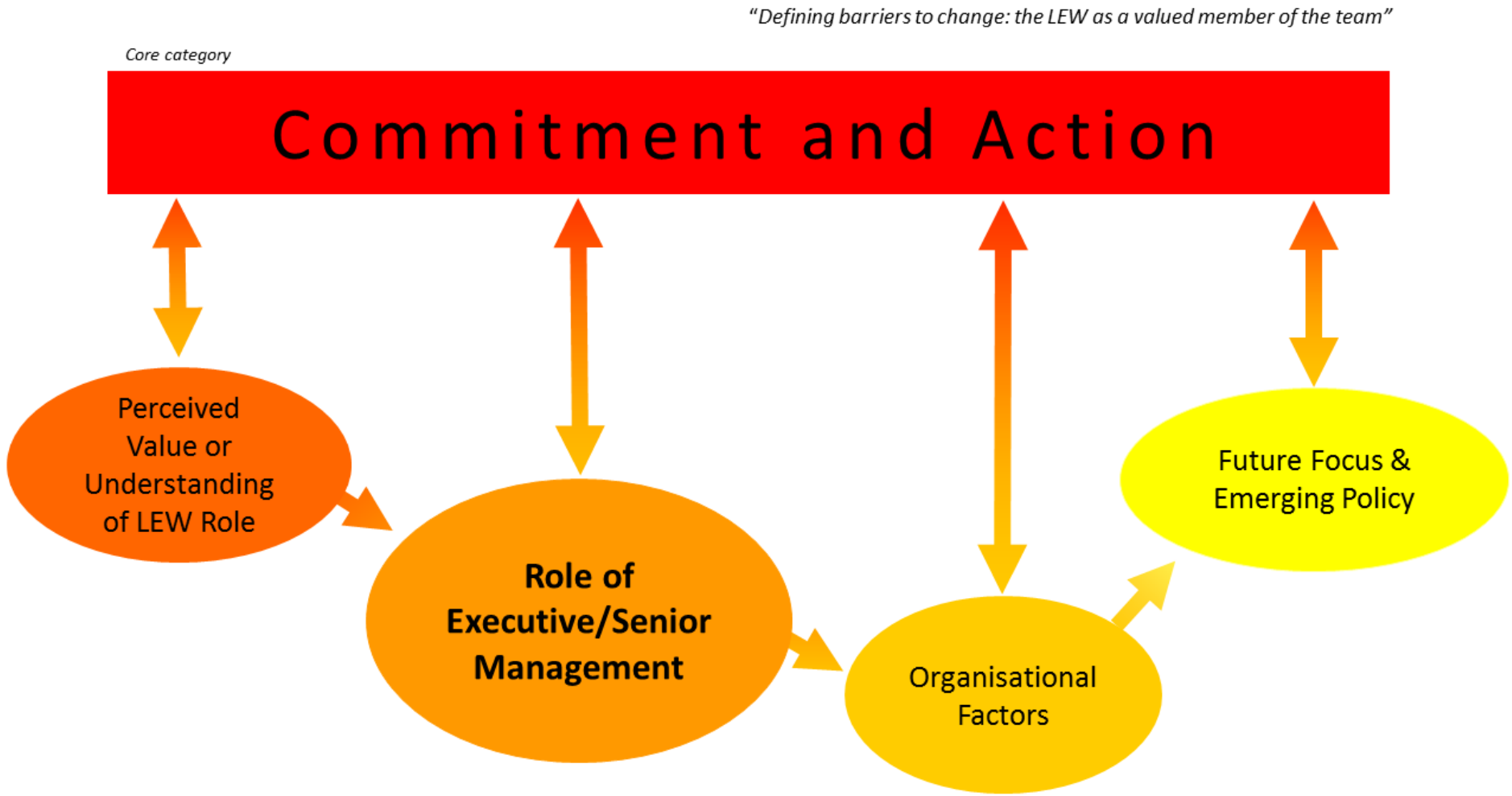
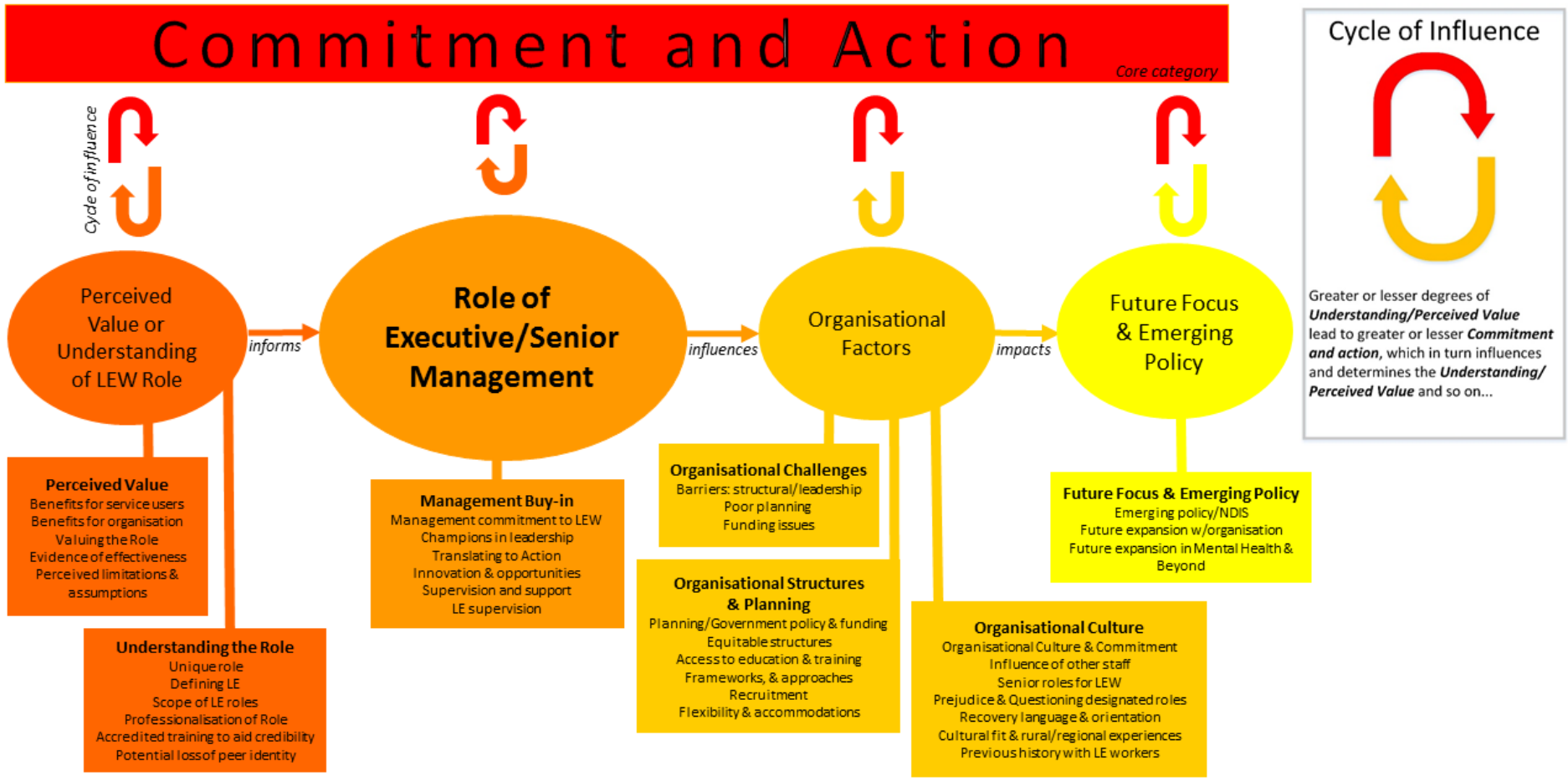


Diagram 2: Substantive theory diagram (all categories and concepts)



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

Findings

Perceived value or understanding of the role

One of the major categories, Perceived Value or Understanding of the Role, described participants' views on how organisations valued and understood lived experience roles, and how participants personally valued and understood the roles.

Perceived value

The value of lived experience roles as perceived by participants was a frequent theme and included discussion of benefits to both services users and the organisation, the way the role was valued, evidence of the effectiveness of lived experience roles and perceived limitations and assumptions.

Benefits for service users

Benefits for service users was a theme common to all participants who employed lived experience workers. These participants enthusiastically described the benefits to service users as a result of lived experience employment:

…the evidence is…from clinical staff and from consumers [service users]*, is that it's* [lived experience employment] *really beneficial to them - Larry*

Lived experience workers 'lived' understanding was seen to give unique credibility to the roles:

…the same way someone who doesn't have children - people just aren't as interested in my advice about how to make your toddler sleep…and I get that and I think that's human nature - Matt

The title or identification of 'lived experience', 'peer' or 'consumer' within the job title was seen to provide positive opportunities for relationship building with service users*:*

That egalitarian relationship, people are openly aware that you've had a lived experience and that, affects the way you disclose your history, information, sharing, sharing of life history and the relationships that develop out of that – Henrik

Penny agreed the inclusion of lived experience in the title aided rapport and relationship building with service users:

It's a trust perspective whether that's from a sense of rapport - that's what I suppose…that [being a lived experience worker] *just endorses something …if we have people with lived experience talking to other people with lived experience - even if they're using standardised evaluation tools or whatever, will provide a different level or potentially a richer level of information than if it was a mental health professional - Penny*

The benefit of decreased power imbalances between lived experience workers and service users was also raised:

…they have a better ability for the service to engage with consumers and carers at a one on one level…consumers and carers would see a person with lived experience or a consumer consultant role as being more equal and being more approachable and it being less of a power relationship – Reginald

Lived experience executive/senior manager Molly offered her view that lived experience workers could successfully discuss topics in a way more traditional roles could not as a result of the decreased power imbalance:

…benefits in the conversations that peers [lived experience workers] *are able to have that a clinician might not be able to have with people…we don't have that sort of authoritative relationship over them* [service users] *so I think sometimes they're more open to having those discussions with us about things*

Lived experience executive/senior manager Matt explains the internal process that enables lived experience workers to challenge service users in ways traditional roles may not be able to:

I think it probably is through challenging ourselves, we probably have a way of maybe challenging other people and exploring recovery in a way that maybe you just can't if you don't stand on that [lived experience] *base*

The unique skills of lived experience workers were thus seen to provide many benefits to service users that would not normally be found in traditional roles. Lived experience executive/senior manager Matt went on to summarise this thinking:

I think we can build and maintain really authentic and mutual connections, I think we can do it really, really fast, and I think we can repair any ruptures to those relationships a lot more effectively because they're built on that genuine, authentic shared experience or shared identification, I think that there probably is actually just a different ability to be empathetic, compassionate and non-judging

Others also spoke of the ability of lived experience workers to empathise deeply or understand the experiences of service users:

Our peer support worker plays a vital role in the mental health support services we deliver because they have that contact with most of our clients and can share that lived experience, so I don't know whether it's a higher level of empathy or a higher level of understanding and knowing what these people [service users] *might be experiencing – Byron*

Moreover, lived experience executive/senior manager Matt explained how lived experience workers provided a living example of recovery and hope:

I think our ability to share hope, knowledge and experience and model that recovery is possible, and also that life is possible while in recovery. That it isn't about this end point and 'I'm perfect now' but actually, I can be wobbly, still competent and still have something to bring to the party, and I don't think you can necessarily model that if you haven't been there or you aren't there

The simple fact that people in lived experience roles have been in similar positions was seen to promote hope:

…they're the embodiment of having been in that position…just the fact that they're back working [lived experience workers can] *instil some sense of 'I can do this' – Josh*

Larry described the impact for service users on hearing some of the lived experience workers stories:

…that consumer was floored and was like 'wow ok' and that's what it does for people - you go 'ok this is, this may not be my life forever there's actually hope here that something can change even, when things are really challenging' …we actually have people [lived experience workers] *in our team do hear voices, that still require hospitalisations at times to stabilise the symptoms of their mental illness and they work and they have meaningful lives and they're having those conversations with our consumers about that openly and people look at that and they go 'wow'*

Lived experience workers were seen to have a unique capacity to navigate the mental health system:

…a peer [lived experience] *set of skills which connects with people* [service users] *around moving through or surviving in or trying to get the best out of the mental health service system - Pippa*

Pippa also shared an opinion that lived experience workers were a valuable source of practical strategies and knowledge that was of benefit to service users:

…if you've lived in that situation for a long time in terms of barriers of poverty or whatever, I think it does help in a practical way…that does shape the way they [lived experience workers] *think, the way they do their work with people. Even simple things about when I put out an invitation to something, I can see the difference with someone who's never caught a bus in their life or tried to get their kids on a bus?*

Overall, the benefits to service users were considered evident in reducing relapse and rehospitalisation as a result of lived experience involvement:

We are using outcomes regularly every couple of weeks with these people [service users] *and so far we can demonstrate quite clearly that intensive* [lived experience] *support post discharge is preventing relapse and is preventing the sorts of predicaments people find themselves in…not only gives us good feedback from the participants but that good feedback generally from the mental health service and other people really buoys everybody and so everyone's proud of what they're doing - Sarah*

Other participants reported similar success with lived experience roles in assisting to reduce rates of hospitalisation and case management:

…people [service users] *spending at least 70% of their time in hospital to having 0% hospital admission and at least 30% of them not even being case managed and we're talking about people being case managed for 15 years and heavily case managed - Bella*

Benefits for the organisation

In addition to the unique benefits to service users, many of the participants outlined benefits to their team, service or wider organisation as a result of lived experience employment. Lived experience workers were considered to contribute to positive workplace culture:

…there is evidence that shows having a recovery support [lived experience] *worker has driven a positive change, not just for the consumers - but within the clinical workforce. The culture of the clinical workforce in that team has changed - Dorrell*

Participants described the specialised knowledge of lived experience workers and their role as a 'bridge' between workers and consumers:

…especially when somebody's more unwell or faced with spending some time admitted to the hospital …our support workers will often call on the peer support [lived experience] *worker for some advice or some clarification…they have a different perspective - Magnus*

Calvin posed there were opportunities for lived experience workers to contribute to training for other staff:

…a number of [lived experience] *workers have assisted with training in terms of sharing story and utilising their own experience in terms of connecting - Calvin*

Lived experience roles were seen to contribute positively to issues of stigma and even challenging some of the attitudes within the organisation:

…it's a deeper understanding of what the stigma issues are. *Stigma's not something that you just see it's something that's ingrained, it's something that's in everybody's psyche. Where the job requirements are not very different, I think it's well worth going through the process* [employing lived experience staff] *even if it was only just to break down the stigma – Josh*

Other participants agreed lived experience could make a strong contribution, including changing attitudes:

… it's probably just that reinforcement of him [lived experience worker] coming along every month and being a voice at the table that I've changed my attitude- he's certainly had a significant contribution - Reginald

Tara, further, saw the employment of lived experience roles outside the mental health sector as a valuable means of addressing stigma at a community level:

I guess our main goal was also you know build a peer [lived experience] *movement because I see the value in it across everything and every part of the community…if we can educate the community, well then I believe we can break down that stigma of mental health challenges with individuals - Tara*

Valuing the role

Benefits to both the organisation and service user contributed to the perceived value of the role.

Byron described the role as vital:

Our peer support worker plays a vital role in the mental health support services…

Lived Experience executive/senior manager Molly described a work environment in which 'allies' (traditional mental health professionals) advocated for lived experience roles:

I didn't have to advocate for these [lived experience] *roles, the* (traditional mental health executive) *advocated and wanted these roles so that's what's been really refreshing is people saying 'we want peer workers in our team how do we go about that' and looking at alternative ways, rather than employing a clinical staff, how do we make that a peer staff? - Molly*

The need to demonstrate value was also raised:

We've worked very hard in this program to empower our peers [lived experience workers]*, to put them out there to be the norm - like they are valuable workers. They work just the same as anybody else and that's just been recognised by the organisation as well, and they've seen the value that we have here - Tara*

For lived experience executive/senior managers the value of lived experience was deeply personal:

…so knowing that somebody had been through what I'd been through and that instilled hope in me, I think that's the cornerstone of lived experience - Larry

However, the value of the role may at times be diminished by unfamiliarity and the perception that lived experience workers may pose a threat to existing roles:

…when we first started there was a lot of fear from the staff that 'oh shit are they gonna be taking over our office' you know 'they better not be doing what we do' - Sam

Within the history of mental health service delivery, the acceptance of lived experience designated roles was seen as a relatively new development:

when I first started working in and around mental health, human services 20 years or so ago, there just certainly was not any type of role that were described in that way [lived experience] *…of course people* [mental health workers] *have their own lived experience of either being a consumer, a carer or both, but that wasn't described or people's own lived experience wasn't acknowledged…I'd say I noticed a massive sort of change - Pippa*

Despite massive changes in the creating of lived experience specific roles, the value of the role was still viewed as variable across organisations, with some lived experience roles seen as tokenistic:

…some of the positions themselves maybe are, tokenistic is probably not an unfair word, or contrived in a way. There are also other organisations or other individuals for whom that really still is very much at the 'you tick box' kind of point - Matt

As suggested by Larry, the level of the role within the organisation may also impact the perceived value:

We have an entry level position called consumer companion which has been around for a really long time and the consumer companion role is, it's a very basic introductory role up on the [part of service] *really just to provide companionship. Through the work we've done, we've identified the consumer consultant worker roles to be - I wouldn't say they're more valued, but they have a high capacity to work with people with mental illness - Larry*

Similarly, Tara identified the need for lived experience roles to be designed to enable the role to reach full potential:

…it's the ideology about educating managers and hierarchy and to do that you have to prove their worth [lived experience workers]*, but to do that you actually have to put them in a position where they can grow and prove their worth - Tara*

Evidence of effectiveness

One of the challenges, issues or barriers for some participants was that they did not have access to enough formal evidence to convince funders, higher level executives, boards, CEOs and other staff that engaging lived experience workers was worthwhile. Whilst those that have engaged lived experience workers have significant 'on the ground' evidence of the effectiveness of lived experience work, they have found that others could remain sceptical unless empirical evidence was available:

I think one of the big barriers as well is research, I think some of where we run into people who really - 'I need it to be evidence based' which is fair enough, but we don't have the necessary evidence base – Matt

Evidence and exposure was also emphasized as a way of combating negative perceptions and assumptions about lived experience workers:

…once we get some hard evidence that a lot of those myths about peer [lived experience] *workers - 'you know they're also taking to claim, they're always on workers comp, they're always fighting with each other, they're never at work' all of that rubbish that people piled up if we can get some good hard evidence and start to disprove some of that stuff then it'll sit on some merits - Josh*

The role of research in improving the perceived value of lived experience roles was also raised:

I think it's recognised in the literature now that it's actually really valuable for people to talk to someone who's had a lived experience or has come before them - Larry

Certainly, the level of employment of lived experience workers varied considerably across the organisations, including some organisations with no lived experience roles. For organisations that did not employ lived experience workers, the reasons were not always clear but did at times seem related to the perceived value of the roles:

I'm really not sure, perhaps it's something we just haven't considered or it hasn't been raised as something that we should be striving towards maybe we don't have a lot of awareness about the value that having a person with a lived experience can bring to a role or a program - Suzie

Sarah suggested the lack of perceived value may be proportionate to a lack of exposure to lived experience roles:

I think it's just a fear of the unknown more than anything - Sarah

Acceptance and expansion of lived experience was often seen to be the result of exposure and success; as noted by Trevor:

the nurse unit manager said she'll do it [employ lived experience workers] *…she's now completely wrapped in the idea of having peer support workers so when something works and other people see that it works people say, 'look I was a little bit reluctant but now we've seen what they can offer we'd never go back to before - Trevor*

This was a consistent theme for many organisations, where exposure and positive experiences led to further expansion of lived experience roles:

And now, now we're just working at strengthening, integrating and growing the workforce - Larry

Larry elaborated to describe what was needed to increase the perceived value of lived experience workers when organisations had little exposure to the roles:

…if an organisation hasn't been exposed to it, they just don't know what they're missing, they don't know what they don't know essentially and it's about again, education and information - Larry

According to Sam, demonstrating the effectiveness of lived experience workers is all about showing other staff the potential capacity of lived experience workers:

…I think you've [lived experience workers] *gotta get in there and walk the walk and let the staff see you do it. You can have all the presentations and all the frameworks and bullshit under the sun but*

no one will pay any attention to it as much as they will you getting in there and walking the walk and showing them what a peer worker can do, I've seen that over the years - Sam

Lilbeth also highlighted the importance of exposure to lived experience roles:

The use of peer workers and the enormous success for when we use them compared to outcomes when we don't, I think we've got a huge evidence base for growing that and our team identify that which is great - Lilibeth

Larry recognised the value of managers who are successfully employing lived experience workers spreading the word about the effectiveness of the workforce:

I think just informing and educating the broader workforce about the usefulness, the evidence, the value has been really useful - Larry

Molly agreed that testimonials from organisations that have had success with lived experience roles could assist in increasing the perceived value of the roles:

…sometimes bringing those people in who've done it well, bringing them into the organisation and talking with the management - what's worked well, what hasn't worked well, the advantages of having lived experience workers- Molly

Sarah held similar views and encouraged organisations looking at employing lived experience workers to contact other organisations that already have significant lived experience workforce to gain advice:

If you're looking at an organisation that's gearing up to take on peer [lived experience] *workers for the first time, I think it's absolutely essential that manager or that supervisor from that organisation locate another organisation like ours and come and have a chat, come and see how the office works, get some understanding about how it can work and how it can be helpful, or how people can be successful in this environment. If they can get that from someone else who's doing it I think that's a really good start - Sarah*

Sarah continued to share her vision of a formalised structure to allow this to occur:

Certainly, it would be great if at some point managers like me and other people employing peer [lived experience] *workers could have some sort of a support group to support people that haven't done it before. So that someone's at the end of the phone for them if they're concerned about hiring someone with a lived experience. Otherwise I think you're just on your own. It's about how brave you are, but if you have someone who's doing it well and there's no dramas to pick up the phone too. I think that would be great*

Perceived limitations and assumptions

Perceived limitations and assumptions about capacity were identified as impacting negatively on lived experience roles:

I think that the main barrier would be management and management view of what a peer [lived experience] *worker can bring – Sarah*

…they asked the question 'what are their qualifications'? And when I was able to answer I think they were actually really pleasantly surprised that we're not just throwing people who have a mental

illness on the wards to work with people who have a mental illness. Which I think that's the misconception sometimes and that's where the workforce doesn't get valued - Larry

Some participants cited a perception that lived experience roles may be unreliable or get unwell as a barrier:

…I think some of the barriers might be perception, so recruiting someone with a lived experience might be breaking down some of those beliefs that people might have in terms of you know 'well what if this person becomes unwell again what do we do then?' - Suzie

This belief was thought by some participants to relate back to wider negative stereotypes about people with mental illness:

…you know anybody with a mental illness is going to kill people or whatever that might look like, those sorts of judgements are still out there - Matt

In Sarah's organisation, the fact lived experience workers weren't seen to be completely 'together' was viewed as a positive motivator for service users:

That sort of peer [lived experience] *support is really valuable and it breaks down the idea that someone has to be a seemingly competent, upwardly mobile, well educated, well qualified, 'together' person to be a good worker - Sarah*

Other participants disagreed with concerns about the reliability or vulnerability of lived experience workers:

…I see them [lived experience workers] as not vulnerable I see them as resilient, awesome, strong people, probably better than the average person you know cos some people get to walk through life with no issues whatsoever and they have no coping skills - Tara

Lived experience executive/senior manager Alex agreed:

I don't fear for a peer workforce I don't hold any fears for us not being robust enough or capable enough or well enough - Alex

Tara also expressed her opinion that lived experience roles being 'out' about their mental health challenges was preferable to the many people employed in the sector who did not disclose:

…you could even say it's better the devil you know than the devil you don't know, because you have so many people in workplaces that have mental health challenges that they hide because of the stigma - Tara

The identified role itself and ongoing prejudicial attitudes about mental illness was seen as potentially limiting for lived experience workers:

I think of workers within our workforce who've moved from lived experience roles into non lived experience, non designated lived experience roles, but that can never be unknown about them. And I'm not suggesting that they would want it to be unknown, but I think it's got to be a pretty healthy organisation for someone to not feel that there's any career limiting elements around any of that so I think people do recognise that you've opened that door, you can't close that door - Penny

Limitations were also considered to be present in the form of risks to the mental health or wellbeing of the lived experience worker:

…depending on their [lived experience workers] *experiences…having an understanding of the issues so that you don't put people in difficult situations where they might be exposed to trauma – Molly*

Limitations were also noted as arising from previous negative experiences with lived experience workers:

…it was just all about his [lived experience worker's] *journey and talking about his story and I don't know, it just felt a little self-indulgent and that he was getting a bit too focused on that and talking about that too much – Reginald*

Other participants also remarked on the need for effective and responsible use of personal story and the fall-out when that was not managed well:

if we have people [lived experience workers] *talking to people* [service users] *about strategies for wellness absolutely they need to be able to manage their own, I've seen it have a very detrimental impact when we have an employee who was unwell talking about their stress and their un-wellness and their frustrations in front of consumers and it distressed the consumers and we had 2 or 3 consumers on this particular day put in a complaint because it distressed them and stressed them out…they're not coming here to listen to somebody else's problems - Larry*

Understanding the role

In addition to the perceived value of roles, participants frequently raised issues around the level of understanding of lived experience work. The category 'Understanding the Role' encompassed a number of concepts, including: the uniqueness of the role; defining lived experience; scope of the roles and potential professionalization and possible implications of professionalization on peer identity and training.

Unique role

Many managers described the lived experience role as very different from other roles and detailing themes of equality as noted by Reginald:

…role is unique and different cos it has a focus on consumers and it's the only role of this sort within the service …I think they [lived experience workers] *have an ability to be seen as more of an equal with the consumers and carers that we work with… so I suppose again it goes back to that power thing that they've actually walked in those shoes - Reginald*

This view was supported by other participants:

…[lived experience work] *very much breaks down that barrier of 'them and us' - Josh*

Byron expressed his opinion that lived experience workers brought a different perspective or view:

…working with people with mental illness is difficult at the best of times and that peer worker can often be almost an independent third party to reinforce what's being said, or another set of views to listen to the story, or somebody else to support them [service users]- Byron

Bella also reflected that the role asks lived experience workers to be more vulnerable than traditional roles:

…they allow themselves to be a little bit more vulnerable in their role as well - Bella

Lived experience use of personal story was raised as another point of difference:

I wouldn't expect a clinician to bring their personal story to the table whereas I would expect the consumer and carer to bring their personal story – Dorrell

Lived experience executive/senior manager, Josh, described effective use of story within lived experience roles:

…the best peer workers never tell their [whole] *story. They use little pieces of their story very infrequently but at the appropriate times to join in empathy with the person they're supporting or to hint at avenues for that person to explore. Rather than this diatribe of a whole story every 5 minutes. I think sophisticated peer workers can use the tenants of their story in particular circumstances to help a person* [service user] *when their hope is failing*

Rather than noting difference or uniqueness of lived experience roles, some participants placed emphasis on the commonalities we all share:

Everybody's had experience of loss, of physical illness or approaching mental illness and mental illness, so we emphasise that. So with these perspectives, the [peer] *support workers they have basically the same responsibilities as the support worker* [traditional role] *and I think that perhaps in other organisations the peer support worker has been a lot more sort of narrowly defined and people have emphasised the distinction between the roles* [peer and traditional case worker roles] *rather than they're parallel. The distinction is the peer worker identifies as having some sort of mental health, mental stress, whatever language you use for it. So the support worker* [traditional role] *might not necessarily identify as having some sort of mental distress even though it might be part of their history - Henrick*

Other participants were of the opinion the greatest difference between lived experience and traditional roles was when it was best to utilise them:

It is similar work, it's just at a different time for clients so more towards the end of service was the way that we used to use that role cos typically for us when people came in there was a lot going on they were in crisis they might have been homeless so there was a lot of sort of practical case management stuff that needed to happen and it wasn't appropriate for that work to happen for the peer support – Oscar

Many participants disagreed, seeing lived experience workers as being similar to traditional roles in terms of scope but also having additional skills:

I believe we are one of the few organisations that the peer workers have exactly the same position as other support workers, they're not supernumerary they actually have a caseload and they work through the case load, but they also assist other support workers where a peer may be needed or the worker may think it would be advantage – Sarah

Bella concurred:

… where they're [service user's] *not needing say a disability support worker because they're not needing that type of high end needs, where they're needing bathing, showering care and personal care, we feel that an intentional peer support worker* [lived experience worker] *can be in that role with anyone with mental health challenges - Bella*

The idea of lived experience workers having something additional or extra was commonly expressed:

The way we're hiring lived experience professionals is we think they're everything that everybody else is and a bag of chips - Matt

Naming what it was that made the roles unique or different was at times elusive and some participants described the process of trying to articulate the difference:

We've done some work in that space and…if there isn't a point of difference then why are we naming the roles? So we've actually sat in a space and gone, logically there must be a point of difference, we just need to understand what it is...consumers [service users] *tell us is there is power in even something less obvious…that the person* [lived experience worker] *doesn't need to share their story that actually the knowledge the person has a lived experience leaves them feeling more supported and more immediately comfortable in that space. I do think they* [lived experience workers] *bring an extra x factor there that is important - Penny*

A concern about the uniqueness of the role being diluted due to poor understanding of the differences was voiced by Molly:

The lived experience roles are very different and that's my concern, if we're diluting these roles and at times I think in some situations we are losing that real lived experience

It was not only managers that struggled to appreciate the distinction between roles, some lived experience workers were also reported to have difficulty distinguishing:

…it was also a struggle for the worker to distinguish what they were doing from the case manager's – Oscar

Matt raised the need for better articulation of roles to identify differences to assist lived experience workers to understand the uniqueness of their positions:

We try to tell people [lived experience workers] *what we think is the plan* [position descriptions/role clarity] *in these somewhat vague, ill-defined ways that include such words as empathy and hope and it's really hard for people to get a finger on that but also they kind of go 'but I'm hopeful and empathetic' or like 'yeah ok' but if we could actually be doing a bit better job of explaining… - Matt*

Defining lived experience

While defining lived experience roles was raised as an important issue, it was also sometimes described as challenging. Challenges included grappling with the definition of 'lived experience' itself:

…'well what do we actually mean by lived and living experience?' People don't want to go 'well this is the threshold that you've gotta meet in order to be card carrying for lived experience' …it means different things to different people. It was not always an easy task to define what lived experience was in the context of lived experience roles - Pippa

Reginald faced similar challenges at his organisation:

Does it mean you have to have had an open service with a public mental health service, does it mean you just have to have had a diagnosable mental health condition, does it mean you could've had 6 or 12 months of really struggling with coming out, what actually qualifies you for having lived experience? - Reginald

Molly was more assured about how she defined lived experience but expressed concerns growing popularity of the roles could lead to people being employed who did not have significant enough lived experience, and consequently did not understand the roles:

…the real perspective of lived experience is to me, someone with ongoing issues with mental health or that live with a significant diagnosis, not just something that they went through for a period of time, so that's a concern I have as the workforce expands, that we lose that real lived experience within the role and that people don't come from the same perspective as perhaps a lived experience worker [should be] - *Molly*

Some participants found it strange broaching the topic of lived experience in recruitment:

It's a really strange sort of process to interview someone for that but really contractually the only requirement is to have a lived experience… that's the requirement, so we have to discuss it a bit in the interview - Oscar

Other participants were concerned about using lived-experience as a means of defining the role due to on-going prejudicial attitudes towards mental health diagnosis:

One of the things is around, 'ok this is my person with a lived experience' or 'this is our peer support worker', it's almost like if you are introducing them to anybody else… I'm going to say something really inappropriate but I don't care… 'there's my person that's had a mental illness' - Byron

Alex questioned whether lived experience was sufficient qualification for the roles:

My understanding or my feel of that is having lived experience doesn't make you a great peer worker- Alex

Other participants agreed lived experience workers needed knowledge of how to utilise their lived experience meaningfully:

Coming with a real breadth of actual experience in that space rather than [just] *a lived experience of recovery, they're also coming with an experience of using that in a work setting - Penny*

Some managers wrestled with the idea of whether people needed to be 'recovered enough' to be a peer worker:

…what I suspect has been the problem is that people thought that they were far enough along their own recovery journey to do that sort of work, but once you get into the role and you know daily you're kind of reminded of what you've been through and you probably have all sorts of triggers throughout the course of the work, so I think that what happened for most people was that they decided that work's just a constant reminder of what I've been through and I'm not up for it '- Oscar

Some participants agreed:

I think there needs to be a reasonable level of recovery - Byron

In Josh's experience people who had not progressed in their recovery sufficiently could become a burden to service users:

If the person is not genuinely [sic] on their own recovery journey and doesn't have the necessary insights that that takes, then they may very well not be in the best position to support others. We have found people who are in that position who have not basically got their own recovery under control can often distance themselves from people accessing the services because those people

[accessing services] feel in fact that they are supporting the staff member [lived experience worker] more than the staff member is supporting them - Josh

Others described lived experience workers becoming unwell as a result of the work:

In the past I don't know that that was really well looked into, peoples wellness it was like 'oh you have a diagnosis you wanna go on to the [MH service location] and befriend people?' 'Excellent! You can be a [lived experience worker]' And then what we identified is that some people aren't actually well enough to be up on the [MH service location] – Larry

Sam's response was however also common, with many participants fervently disagreeing with the idea of being 'recovered enough':

That's the biggest load of bullshit I've ever heard in my life, I mean a lot of people are in recovery and they have relapse, so relapse is a normal part of life. So we have ups and downs, I've had my ups and downs and as a matter of fact I'm on a bit of down and out… but you know just say you're not recovered enough to do this job's a load of bullshit - Sam

Octavia agreed and went on to describe an effective lived experience worker in the acute setting she works within:

…someone that had quite chronic schizophrenia as a diagnosis but they have that ability to take on education and to understand both contemporary as well as medical based model… and also be able to discuss issues that arose within the unit with other consumers. Being able to go and talk to consumers in the inpatient unit which was my focus, and have those conversations with unwell people and not shy away… trying to motivate and have lots of ideas about different things that would benefit consumers when they're in that acute phase of being unwell - Octavia

Lived experience executive/senior manager Matt explained the complexities of recovery and how difficult it is to define how recovered someone might be:

I don't think it's actually about a level of recovered …this is this idea that recovery is linear and that it's somehow maps to your ability to do work. I can be really awful in some ways while at the same time being really quite good in other ways, …I can be having you know a terrible time personally and be really on fire academically, or be really struggling at work for whatever reason but you know my relationship is going great - Matt

Scope of lived experience roles

In addition to defining the lived experience that informs the roles, participants discussed the scope of roles. Lived experience roles were described as diverse and varied even within organisations and same role titles:

We have other peer workers that are what I call more advanced - do more than just sit around and play games and talk to people, and they go down there and coach wellness and help people identify their early warning signs, their triggers and help them come up with strategies to overcome that – Sam

Some participants described the scope of roles expanding over time:

One of the other struggles for us was over time the peer support worker sees the work that they do as being similar to what the case manager are doing, so then they start questioning 'well why is my role different, why can't I do all this extra work' so that sort of lead us to a different approach - Oscar

Oscar further noted that updating the position description gave parameters for the role:

so the position description is clear now that it's a case management role with an element of peer support - Oscar

It was noted that lived experience roles extend beyond direct support as indicated by Trevor:

They sit on employment committees for all senior staff …they sit on every committee for psychiatrists, NES unit managers, team leaders and above - Trevor

The need for career pathways to extend the limits of lived experience work was also highlighted:

…career pathways that's exactly right and we have some peer workers who've moved into management roles - Josh

Some participants believed it was important to allow lived experience workers to input into the scope of their own role:

So my role there was to get a vision… of how peers want to be treated and how they saw the role recommendations and implementations …what we agreed on was we would give people who wanted something different what they wanted, and those who wanted the standard one that the other support workers got - everyone had the option. Give people what they ask for and you're probably getting a better result – Bruce

Professionalisation of the role

In addition to the scope of roles, professionalisation of the lived experience roles brought a diverse range of opinions.

Some participants described professionalization as a naturally occurring phenomenon – with the skill sets of lived experience applicants increasing over time:

…one of the big topics was the professionalization of the peer worker role. So that the people are getting educated, the people are coming to organisations with a full range of skills and abilities, and qualities and the expectations were higher than perhaps they had been in the past.' - Henrick

Some participants believed some type of mental health qualification was necessary to allow lived experience workers to be successful in the roles:

My thinking now is that they [lived experience workers] *need to have a qualification in mental health work so that gives them some sort of a framework to understand what the work is, what it takes to assist someone struggling with mental health issues… and ideally we'd be looking for someone with experience but that's not essential - I think it really must be a bit of a struggle for someone to do a peer support role with no exposure apart from their own experience - Oscar*

For an organisation not currently employing lived experience workers, formal qualifications were also seen to aid the perceived credibility of the roles:

I see affirming people with qualifications is helpful, I see a structural allocation of a particular qualification as adding power to the role …I would think if we were employing peer workers we'd look for some qualification such as that which would help people feel validated and be more qualified - Calvin

Tara agreed professionalization was needed to increase the credibility of lived experience roles within the wider workforce:

I'd like to say it isn't, but realistically in this world everybody needs a piece of paper, so I think it's good that it's now being offered, because they deserve a piece of paper you know and what it means for them to be valued as a professional worker - Tara

In addition to formal qualifications, credibility was also linked to how professional lived experience workforce culture was perceived to be:

It's certainly not recognised as a professional workforce, I'm probably stereotyping but they're not professionals, they're people with lived experience, bit of a general statement but I don't know if everyone sees the value, which is coming back to communication and education and integration into the workforce. I think it needs to be highlighted as more of a professional culture …to sustain them [designated lived experience positions] *in the workforce - Octavia*

Accredited training to aid credibility

The nationally accredited Certificate IV in Peer Work was not considered essential or the final word on training, but it was considered a move in the right direction to add credibility and recognition for lived experience roles:

…being able to offer our Mental Health Cert IV in Peer Work to both; our participants, workers, community members, so we have registered doing that course now. It's not the 'be all and end all' I know, but I think it's a start… it just gives them [lived experience workers] *another scope and …also a qualification to be able to say 'well actually you know what? Hey I am more than an expert, I am a recognised expert too' – Tara*

Byron agreed the Cert IV may increase the skills of lived experience workers but did not see it as essential to the positions:

I see often that qualification can enhance the skills that they [lived experience workers] *have. I don't see that it actually needs to be necessarily a criteria for the position itself… I value it however I also know that sometimes when people are doing a certificate 3 or a certificate 4 they can question some of the content - Byron*

Some participants saw the value but also felt other qualifications could be equally beneficial:

The fact there are now specific qualifications for lived experience that were developed by people with lived experience amongst others, it's really fantastic and we encourage all of our staff to go through that, but I think that other qualifications can be just as beneficial - Larry

Oscar acknowledged that qualifications may allow for more recognition to do case management as part of a lived experience role:

…over time this [lived experience] *worker gained more experience and got more familiar with the role, wanted to do case management but they didn't have a qualification, so we assist them to do a Certificate IV in mental health work so that as an organisation we knew they had qualifications to transition to case management - Oscar*

Other participants described a potential for greater stability for lived experience roles:

Around the Certificate IV, although in our role descriptions we put in that it's desirable, however when people come in to the roles we encourage them to apply for the Certificate IV in peer work and mental health so I think sometimes it can be around convenience and stability - Molly

Potential loss of peer identity

Peer identity was linked to holding onto the uniqueness of lived experience work and was also expressed as a fear of being 'co-opted' by the more dominant clinical and medical ideologies. Lived experience executive/senior manager Jane shared some of her experiences:

I definitely have personal experiences of feeling like I started to look like I'd been co-opted, or wondering if I should start doing it like everybody else, but then I also have experiences where people think that a peer worker role is exactly the same as any other role and I think it's a little bit more obvious in a clinical setting that at the end of the day people have to enact the [mental health] *act. That's a very clear distinction in power based role compared to a lived experience role - Jane*

Another lived experience executive/senior manager Sam, expressed a conviction that protecting the uniqueness of lived experience roles was essential:

…we wanna keep our identity and our uniqueness in what we do and you go calling yourself clinicians and mental health practitioners and everything its gonna get all muddled up and, and it yeah I spose I'm anti us becoming part of the medical model - Sam

While acknowledging a risk of being co-opted, Alex, also a lived experience executive/senior manager, pointed out that lived experience roles deserved professional recognition:

…is that [professionalisation] *part of being co-opted into traditional services? But the fact is we have the system we have and people are coming and seeking or being helped to seek support* [from lived experience workers] *so why not offer something that's also in that space. That is worthy of professionalization - Alex*

Additionally, Alex questioned the somewhat contradictory service requirements of reporting while maintaining the peer identity:

I'm still trying to work out how to maintain the real fundamentals of peer [lived experience] *work and how you report how you engage. How you capture that information and keep it really 'peer'- Alex*

Similarly employed in a lived experience executive/senior management position - Larry was confident of not being co-opted, citing the value he felt the organisation held for lived experience work as a protective factor:

I don't have any concerns about our workforce being coerced to be more clinical or anything like that I think it's actually really welcomed and valued that we have the lived experience workforce - Larry

Lived experience executive/senior manager Molly acknowledged a temptation to sometimes mimic traditional roles rather than always using the lived experience story to inform work practice:

…it might be easier than sharing lived experience - easier to be more task oriented you know, working with - for example - occupational therapists in an inpatient ward running groups. And I know it can be really challenging for people, how they best share that story, so I think it can be tempting to fit more into a role where you don't have to wear that, where you don't have to share that experience - Molly

Peer identity was also raised as the balance between identifying as working from a lived experience informed practice without being negatively labelled or 'othered', as expressed by lived experience executive/senior manager Henrik:

It's really important to me that you know that we're [lived experience workers] *people first*

The peer identity was also considered essential in challenging stigma, as explained by lived experience executive/senior manager Matt:

…there's really something about challenging stigma that is about getting out there, that really changes perspectives from the people who we provide support to - to ourselves - to our co-workers - to you know, society at large that you just can't achieve in the same way if you haven't been there and you're not wearing that tag - Matt

Role of executive/senior management

Executive/senior management Perceived Value or Understanding of the Roles was seen to directly inform the Role of Executive/Senior Management. According to participants, the executive/senior manager was the lynch pin in whether the idea for lived experience roles translated into action.

Management buy-in

The degree of management buy-in included the degree of commitment the manager had to lived experience work, and the leadership they showed in championing the lived experience roles. It was considered critical that management commitment translate into action. Creating innovative opportunities was also raised, as was the need for supervision from both traditional and lived experience roles.

Management commitment to lived experience worker

Participants frequently stressed that support for lived experience needs to come from the top and that executive and senior managers need to be on board:

…it comes back to the beginning of our conversation when we talk about having execs on board - Larry

Sam was in agreeance:

…from my experience… [the success of lived experience roles] *is dependent a lot on the health service anyway and the manager you have*

It was seen as an endorsement when managers were supportive of lived experience roles:

…it sends a message to staff and the relevance of the positions that middle management need to be very supportive of the roles. I know in the inpatient units where we've had the nurse unit managers some that've been very supportive of the role…those roles have developed a lot of respect from the staff because that nurse unit manager is very supportive of the role, so I think that's really important that you get buy in from the management - Steve

Top down support was seen to promote the value of the roles and ensure engagement at all levels of the organisation:

I think the service needs to be very visible in its support of employing [lived experience] *people and it definitely needs to come from the top down because otherwise it would be easy for staff to brush it off or you know put up barriers that don't need to be there so it just needs to be quite visible and, and open point of view from your service that that's the way you do business and that's the way we'll accept it - Magnus*

Commitment from different levels of management was seen as essential from the beginning of lived experience employment:

…team leaders supporting it from the very beginning, making it very clear from the outset that this is something that's vital - Jane

In Byron's view a commitment to lived experience roles also demonstrates an organisation's confidence in the ability of service users:

…we all talk about dreams and as Mental Health Programs, we talk about hopes and goals for the future and all the rest of it, but as an organisation that employs people to support people with mental illness if you're not prepared to employ them [people with a lived experience] *yourself well, what sort of a hypocritical organisation are you? - Byron*

Larry concurred that this was more than a commitment to a workforce but also a commitment to what that work force represented:

'because you're then investing in hope, which means we're investing in people's personal recovery not just their clinical recovery…my belief is you cannot do clinical recovery without personal recovery otherwise that person will just keep rebounding back' - Larry

Management commitment manifested in a number of ways, including personal commitment:

I've always had a bit of a passion for peer [lived experience] *work' - Tara*

Molly relayed an example of financial commitment from a senior staff member leading to significant lived experience role development:

I had a really strong supporter who was the manager… and she had some funding available and was flexible with the funding. That was clinical funding we used to develop some peer [lived experience] *roles so it's getting those sort of people on board…and we were able to do that even though I'd been pushing through management to get these roles without any effectiveness…so I think it's looking beyond the scope sometimes and moving around those people that aren't so supportive - Molly*

The personal beliefs of managers were seen to influence the degree of commitment they showed towards lived experience workforce development:

some people do it better than others, some managers are more on board with peer work than others…I do know some managers aren't all that happy having peers - it's an imposed thing, but they're seen as a bit of a deficit and I don't think they truly value peers - Bruce

Champions in leadership

In addition to managers demonstrating some commitment to lived experience work, the role of executive or senior management 'champions' - people who would actively promote and support the roles - was seen to further assist in the success of lived experience workforce:

These people were recognised as 'champions' in supporting and advocating for lived experience roles, definitely the fact that he's [lived experience worker] *had a champion in* [name of senior manager] *and someone that is completely supportive of him and his role - Reginald*

Champions in positions of authority were also seen to assist with the growth of lived experience roles:

…that then rolled into the peer [lived experience] *worker roles and* [senior lived experience colleague] *took up that challenge with gusto and since we've rapidly increased the number of peer workers – Josh*

Particularly in relation to prioritising and resourcing the roles adequately:

… it was endorsed as being important enough at that executive level to really warrant full resourcing in a serious way so it wasn't just - 'oh we need to have a look at that, let's have a meeting' it was full and considered resourcing and that certainly was realistically championed - Penny

Part of the role of champions was articulated as being prepared to argue and stand their ground:

I think it's unique having somebody like [senior lived experience colleague] *who's not backwards in taking a step forwards, to be able to have those ding dong battles and not fall out over it and people who think you can do this without having really robust and I'll say the word arguments, or discussions about this sort of stuff, it's the details in those arguments - Josh*

Alex identified the importance of champions in high places who publicly identified as having a lived experience:

I think we've been very fortunate to have some people who do champion and are identified [as having a lived experience] *and have a high profile in the health community - Alex*

The role of champions who did not have a personal lived experience was also highly valued:

There also some people who probably don't get recognition that they deserve, who don't identify but also champion the lived experience workforce and they are incredibly supportive and that's just as vital and it also creates safety for others – Alex

Translating to action

Related to the degree of management buy-in, the success and growth of the lived experience workforce was seen to rely on management commitment being translated into action. This required lived experience workforce development having some degree of priority:

…we've been hearing about likelihood of lived experience workers coming into the workforce but there's been nothing really, no discussion, there's no emphasis on it…but it's very much lots of Band-Aid work at the moment, very busy, high caseloads just trying to keep people as well as we can in the community and provide you know maximum support with limited time, so I think there's just lots of different focuses and I don't think its necessarily the biggest priority - Octavia

Lilibeth faced similar barriers at her organisation:

…at the moment nothing has really progressed in that peer space and what that looks like because they've got other pressing thing[s] - Lilibeth

Conversely, when executive/senior management did give priority to lived experience roles, expansion and growth occurred:

we had [a small number of] *peer* [lived experience] *workers when I took over here, we've got* [many lived experience workers] *now' - Sarah*

According to participants, management action needed to be thought out and meaningful, rather than just tokenistic measures or 'lip service':

…we get told a lot of things, for instance we're gonna have lived experience people, consumers on our interview panel - so everyone goes and gets a consumer with no real criteria. We generally used to use the same consumer all the time and there's no real thought, there no bonus, like what are we adding to it? We're doing things exactly the same except we can say that we've got someone on the panel - Octavia

Lived experience executive/senior manager Alex cautioned that action and change takes patience and an understanding of the system:

I think sometimes you can be too militant and too demanding of huge systemic change which the system can't handle, you can't completely tear something down and start it again - Alex

Innovation and opportunities

Translating commitment to action was also reported to include making use of innovative opportunities. Reginald noted that organisations were more likely to be successful with lived experience roles when they were innovative and open to change:

How innovative the service can be or you know how innovative the service has been and how open they are to change and doing innovative things - Reginald

Trevor also identified the need to take risks and experiment:

…all we can say is you've gotta be prepared to experiment - Trevor

Opportunity as reflected by Pippa, may be identifying an organisation's readiness and taking advantage of 'the planet's aligning'

I think it's a combination of the, the planets need to align so there's enough that the organisation… actually need to see what's in it for them like on a really mercenary level, then there needs to have people with the skills, experience and I think it involves a skill set which is also developmental and I'd suggest if there's been lots of focus on just pure clinical background its harder to move into a developmental sort of space, with a peer workforce where it's about change its about needing to modify and improve systems and I don't know it seems to be harder for, for people who have just been doing, or even just doing direct service delivery all the time. It is that readiness so like in my work I think a lot about what is the readiness for the place in a space to take on a different way of working or to expand the way that we work - Pippa

Supervision and support

Most participants did not see that there were any differences or specific challenges in supervising and supporting lived experience workers in comparison to people in traditional roles:

I talk about it not being peer [lived experience] specific but actually just being good management. I think good management is compassionate management and empathetic management and holistic - Matt

Tara held a similar opinion:

They're [lived experience workers] really no different to any other worker, we all have our challenges in life - Tara

Tara elaborated, how the life experiences of lived experience workers could also make them more resilient to workplace stress and/or having insight when they might need to seek support:

The peers [lived experience workers] are actually more proactive which I think is great because they know themselves and they know their limitations- Tara

Some participants stressed the importance of creating workplace cultures where people feel safe to be themselves and disclose distress.

…we really have tried to build a culture where people walk through the doors their whole person, they don't stop outside the door and 'mask'. We really want people to come in with all their quirks and bits and bobs that make them interesting, because we think the work we do is the work of relationships and people actually have much better relationships with humans than they do with 'roles' so really we try to hire for a whole person – Matt

Matt continued to describe a working environment in which genuine care was emphasised:

…we spend a lot of time investing in relationships kind of within our team. When push comes to shove we really are able to pull together in what I think is quite an unusual and fantastic way to get stuff done and I think that's because there is that…kind of closeness…that genuine care- Matt

Having an open door policy was raised as important to effective support:

… I've got an open door policy. They [lived experience staff] understand that they can get some debriefing, they can get a bit of feedback, not advice but just feedback, and they really enjoy it and I find that they'll do that regularly. To come in and just feel safe, feel happy and then move back out - Sarah

In Byron's case, the open door policy was across the organisation:

…all of our organisation has an open door policy so he [lived experience worker] has no issue in coming and speaking with me or the chief executive- Byron

Some participants described a variety of supports and supervision available to lived experience workers:

we have scheduled supervision, there is an offer of external supervision as well but I have an open door policy also because …an employer has to be aware just like things can upset the average person some of our peers [lived experience workers] can be triggered by different things. Particularly working in a difficult workplace like this - Tara

Many participants expressed a preference for informal modes of supervision and support:

I think the Informal's actually even better than the formal - Byron

Alex agreed that ongoing reflection and feedback could be more effective than formal supervision:

It's not so much about supervision it's just about constantly or consistently reflecting. And being able to reflect and I think we've created a culture for the time being …that it's ok to say 'hey I'm flagging this, I'm really struggling with this today'- Alex

A knowledge of recovery was deemed important in the supervision of lived experience workers but other qualities of supervision were also described:

I personally have supervised a lived experience worker recently and it needs to be somebody that is recovery focused, has a good understanding of the government and the processes and things, good mental health background, quite a lot of knowledge, and somebody that's able to be quite empathetic…preferable someone that's actually worked and been able to listen to lived experience workers - Octavia

It was also suggested by Sam that some senior managers may have difficulty accepting when lived experience workers might require someone with knowledge or skills they are not able to provide:

… they just don't like thinking that …they [lived experience workers] *may need some sort of supervision they're not capable of giving, they just don't like it, the arrogant ones don't anyway- Sam*

Lived experience supervision

While the value of supervision from traditional management roles was acknowledged, lived experience supervision and support was also considered necessary by some participants:

…supervision and coaching being something any line manager can do with any worker, but the mentoring component …when you're mentoring it's around saying 'I have, I'm sharing some of my', I mean that's the purpose of mentoring. With the line manager saying 'look I've had a similar experience here it might be useful if I share that with you, would you get value from that?' but if the manger themselves is not a lived experience worker and the person is wanting some mentoring around purposeful use of their own lived experience and the work that they're doing, their manager is of no use to them – Bruce

I think it is really important that people [lived experience workers] *then have supervision - which is a supportive manager or supportive structure, but also then to link with other peers* [lived experience workers]*, with other people who are also being treated like shit in other teams…I think supervision's really important because it's not only is the worker doing okay but it's also is the organisation doing okay by the worker, and I think supervision is a medium whereby that at least can be checked - Pippa*

Supervision of lived experience workers by people in lived experience roles was viewed as a safeguard in maintaining the uniqueness of the peer role:

…I think there is a huge risk in it for a number of reasons whether that is because the [dominant clinical] *culture just pulls you* [lived experience worker] *back that way. Because you know that's the strongest voice, your voice gets a bit lost or because you lack confidence you feel a bit lost or you haven't had the training and support to know what your role actually was in the first place. Because there's a lot of dynamics, but being co-opted is very real and I think that's the reason why supervision and having co-reflection kind of thing with a peer* [lived experience worker] *is really important - Jane*

Lived experience executive/senior manager Bella shares experiences from her lived experience run service where all the roles are lived experience:

it's so important, you wouldn't be able to come in everyday do the work you do, I mean we have workers that, they say together they'll spend that time [providing co-supervision for each other] they'll spend half an hour sometimes longer in a shift when they need to, it doesn't necessarily have to be with [lived experience manager] or myself, they can do that together

Sarah's team also provided strong support for each other:

The other members of the team can recognise when someone's becoming unwell and they can ramp up their friendship and support

Bella reflected on the need for ongoing support and co-supervision across traditional roles as well:

I don't know how people can do it [work in mental health] *in any role without doing this type of thing* [lived experience style supervision and debriefing]*, and that's why we're trying to introduce co-reflection for managers who are in the mental health team not necessarily working with IPS* [lived experience] *workers but coming from those values on how they support their workers*

Organisational factors

Participants viewed Organisational Factors as a direct reflection of the Perceived Value or Understanding of the Roles by executive/senior management. The major category Organisational Factors detailed a variety of issues relating to challenges faced by organisations in planning for and employing lived experience workers, organisational culture and commitment, and the structures and planning needed for lived experience workforce development.

Organisational challenges

There were several challenges broadly identified by organisations as; barriers within existing structures and leadership, insufficient or faulty planning and difficulty accessing funding.

Barriers: structural/leadership

Many senior managers described barriers with existing organisational structures. In some instances, this presented as initial resistance within the organisation:

Well look I don't think we're any different to anywhere else, you know there's initial resistance…- Trevor

There was also some suggestion that some of the organisational barriers may have been the result of stalling or blocking by high level management or organisational processes:

I think one of the barriers to getting this [lived experience work] *on board has been perhaps a centralised source of power and it's taken a long time to get documents endorsed and to get on with it. So, I think perhaps that's one of the barriers - Henrik*

Some participants described management not having commitment to the lived experience workforce as a significant barrier:

I think that the main barrier would be management and management view of what a peer [lived experience] *worker can bring - Sarah*

Others felt there was no ill intent but that organisations might not support or know how to support a lived experience workforce or that establishing or growing one it might be a lower priority to other things:

…organisational culture is a big one and I don't think in [this health] *service that the senior management culture is an active obstacle or a barrier, I think there's a variety of reasons why we might be slow out of the blocks. Financial reasons, just a variety of other priorities that we've needed focus on, like the opening of the new hospital and so on, and there's only so many hours in a day so I don't think there's any ill intent behind it but I think we can certainly now move forward - George*

A lack of staff buy-in and appropriate training for lived experience workers were identified as potential barriers:

…there was limited value in the position from a staff point of view because of the issues and the lack of support organisationally. Certainly now I think that because there is more of a focus on recovery and consumer orientation and consumer journeys that we do support lived experience workers within the workplace - Octavia

Even for organisations with high employment of lived experience workers, challenges had to be overcome and the experience was described as a '*learning curve'.* It was notable that organisations referred to the time it has taken to effectively integrate a lived experience workforce:

…biggest barrier I've seen overcome is it's just taken time - Trevor

Being the only lived experience worker on a team was thought to add difficulty to the role:

…even though they [lived experience workers] *were in a team, when you're the only person doing a role you have colleagues but they're different, you don't have anybody that directly relates to you in terms of your work, so you don't have a peer that you can go and say 'how are you going with this? Cos I was struggling with these things' - Henrick*

Separating the lived experience workforce and not integrating them into the wider workforce was also considered to create barriers:

…one of the barriers sometimes the organisation will create a peer workforce of a few people and have them sitting out on their own - as in a different enclave and suddenly they become precious, some of them feel isolated within their own workforce and that's where it starts to fall apart. People [in traditional roles] *go 'oh that doesn't work'. So the peer workforce needs to be completely integrated within the organisation. Danger being, if it's a separate little entity and there's a squeeze in money it's easier to cut off a little entity that's sitting out on its own then selectively do it from out in the workforce to make redundant. So it needs to be integrated into the organisation - Josh*

Larry also raised the need to meaningfully incorporate lived experience workers as part of the wider workforce:

With the fact that they're [lived experience workers] *now part of the multidisciplinary team if you just throw them in there and expect them to go and do their job autonomously, they're not part of the team, the function doesn't work most of the time, people didn't know who they were - Larry*

Support and supervision, particularly within government agencies were viewed as critical for the success of lived experience roles:

…some of the hurdles with employing such people [lived experience workers] *is the support and the supervision of people when they get in those positions to ensure their transition into the government agency in particular - Octavia*

Octavia continued to describe existing policies and procedures that were time consuming to navigate, and in her opinion constituted a significant barrier:

I think it's one of the biggest hurdles is people [lived experience workers] *may be disheartened by the process and policies and procedures because it's quite difficult once you get in here. It's good to do different interventions and have ideas and want to make change but it's quite difficult to do that within the environment, everything takes a lot of time and no matter it's lived experience or another topic, it's quite timely to get anything into place - Octavia*

Structural issues also inhibited progression when limited opportunity existed for career advancement:

Look it's very hard in a lot of our programs so if you look at [names a Mental Health program] *for instance there's only really 2 roles, you are either a support worker or peer* [lived experience] *worker - Bruce*

At times, it was recognised that existing models of lived experience work may not easily fit into organisational demands and structures and at times might require adaption:

IPS [lived experience discipline] *in its most fundamental would not probably fit into organisational demands but there can be a little bit of a marrying of the two - Alex*

Poor planning

A significant challenge raised by participants was poor planning for lived experience workforce development. Poor planning was seen to contribute to situations where lived experience workforce development appeared rushed, and where the foundations for understanding and communication were not well established:

I think it was very much 'we're getting this money to do this, it's gonna be great to have this fresh idea' …rushed like a bull out a gate - just get people in positions and not actually think about whether they're right for that position - Octavia

Bruce suggested a strategy for ensuring adequate planning occurred:

Sort it out, connect as a whole of organisational team - that can be really difficult if the organisation's really big, but I think even if it's team by team by team, it's possible and when we don't do it [adequate planning] *these are the kinds of things that eat away at the culture and they cost time and money and energy - those are the kinds of things that get in the way of peer* [lived experience] *work and recovery orientated practice - Bruce*

The need for planning was thought to include such processes as developing position descriptions and providing adequate training.

…but what they didn't do was provide any training or any skills, there was absolutely nothing and trust me I tried to find out…, but you would think once they had introduced that [lived experience] *role they would say 'this is what a peer is and does' – Bruce*

Similarly, Octavia was concerned about potential lack of training and support for lived experience roles:

I'm still apprehensive that they would have the appropriate training as well as support if they [lived experience] *were to start - Octavia*

In other instances, planning had occurred but little action:

We've designed a position description, we've talked about it and talked about it, but things are very slow in progressing - Henrik

Some participants spoke about how better systems evolved over time and perhaps some of the 'false starts' may have contributed to the necessary learning, as Alex explained:

It wasn't always hunky dory here and it's not always hunky dory now, I mean there were some pitfalls very early on. When there was a bit of a lack of direction and guidance and understanding, or just framework …But there had to be that learning to get to the point where we're at - Alex

The consequences of poor planning including recruitment of people who may not be suitable for lived experience work, however, was seen by some to make it more difficult to enlist support for lived experience workers:

…if we recruited properly and we had peer [lived experience] workers who can actually do the work then consequently they don't face stigma especially within our organisation, but as we bump into other organisations …other organisations who are maybe not as mature as ourselves, that whole thing starts to unravel - Josh

Larry provided an example of what happens when recruitment is poorly planned:

We have some very long standing people in those roles …so they're essentially permanent staff - managing them out would be incredibly hard even though they are casual employees and if I'm really honest, some don't add a huge amount of value - Larry

Poor planning, lack of clarity of good structures were also seen to leave lived experience workers vulnerable and unprotected:

For so many years we've been running these programs and have been rostering [lived experience workers] *… half the time people think they're a consumer they don't even know who they are and where's the protection and the safety around that for my workforce? There's none, which is why again I want to get that model and structure and everything figured out because I want to make sure that governance and those reporting lines and everything is concrete - Larry*

Matt spoke beyond individual organisational planning to the need for the sector to engage in wider planning aimed at 'growing' the lived experience workforce:

I don't believe that it's [lived experience workforce] *growing with a lot of purpose or foresight. …There's some risk that in a few years' time will be looked back upon 'oh that actually isn't necessarily useful of delivering x, y and z outcomes' because we weren't purposeful and intentional about that to begin with…We need to have a really good sit down and talk about why is it we want* [lived] *experience professionals in our team and throughout the system and woven in, and what is it we're actually trying to achieve?*

Funding issues

In addition to planning, many senior managers described gaining (or not gaining) adequate funding and/or resources as a challenge in getting lived experience work off the ground:

…that's everyone's challenge getting more resources to grow - Larry

Lack of understanding of what resources were needed was also cited:

I think the jury's still out cos a lot of these things are about resourcing and as an organisation what would that look like, [to] *resource a place like that* [lived experience space] - *Pippa*

Lived experience executive/senior manager Alex spoke about how new and ongoing funding pressures are making it more difficult for lived experience workers to find time to 'sit with people' which is one of the things many managers identified as an important feature of lived experience work:

…as the demand on the service and the demand on the resources of a service grow…you don't feel sometimes that you're getting to enough people with enough time - Alex

Larry also notes that relatively small numbers of lived experience workers also puts a strain on time and availability:

…there's just not enough of us, it's challenging

Organisational structures and planning

While the sub-category Organisational Challenges introduced unhelpful practices, Organisation Structures and Planning details the proactive approaches organisations have used to support lived experience workforce development.

Participants described the need for organisations to plan and lay the structural foundation for a lived experience workforce. Preparation involved developing frameworks, consultation and establishing processes of communication.

Molly described the process undertaken at their organisation:

…between 3 and 6 months of conversation, preparation…getting our evaluations or our framework in place, figuring what tools to use, and we went through a whole process of saying 'alright let's get people with lived experience'. Then we strategized around 'so what are our partners, how do we do that, how do we reach out and find the right people'? - Molly

Other participants described the need for consultation in the development of lived experience roles:

…there needs to be a wider discussion or forum to discuss how it could look…instead of that authoritarian approach 'this is what's happening and this is what's gonna be done' - Octavia

Henrik emphasised the need for position descriptions and clear definitions:

…as I've worked in the role it's been a learning process…we've moved along and it's from that experience that we've drawn up the position descriptions for peer support [lived experience] workers so we have expected there'd be less of a learning curve for the people we employ - Henrick

There was a sense from some participants that much of the learning has been organic and although more planning is required, some merit and value was attributed to the 'Just do it' model of development:

I feel a lot of these spaces with peer [lived experience] *work is about a conversation that keeps on keeping on – Alex*

Tara held similar beliefs and had words of encouragement:

I just would say have a go - Tara

Planning/Government policy

The degree of planning and commitment to meaningful lived experience workforce development was also linked to Government priorities and funding. Government policy has had an instrumental role in the peer workforce and this was evident in the mandated peer roles that formed the nationally rolled out 'Personal Helpers and Mentors' program:

On the philosophy of personal helpers and mentors, and it being a recovery framework and the need to have someone on the team as a peer [lived experience] *support worker…a couple of guiding principles documents articulate that - Bruce*

Equitable structures

Equitable Structures were viewed as an important part of organisational planning that allowed equal opportunity for all workers within the organisation, including career progression and support.

Josh described equitable opportunities for career progression at the organisation where he works:

If new positions come up for this level [sic] both peer [lived experience] workers and mental health workers are allowed to apply…If we got a senior mental health worker job vacant, it automatically becomes a senior mental health worker/peer worker or peer worker/mental health worker and anybody can apply for that job and obviously if a peer worker gets it, becomes a senior peer worker position if a mental health worker gets it becomes a senior mental health worker position and that's based on merit…and we have some peer workers who've moved into management roles - Josh

Bruce concurred:

So the sky is the limit, we don't put ceilings on people- Bruce

Support structures were seen to be of benefit for any employee regardless of whether their role was designated lived experience:

All of our support structures need to support all of our staff because who's to say a person doesn't have a lived experience or a person does have a lived experience? - Josh

Other participants agreed with a whole of organisational approach and saw it as a means of combating stigma:

…when you shift the frame and you're introducing [support or policies] *in terms of a whole of organisation, what you're actually doing is de-stigmatising as well - Penny*

Structures also encompassed inclusive policies and platforms that distributed power and minimised imbalances. Similarly, these policies and processes were viewed as relating to all staff:

Overall polices and processes - and not so much that it applies only to those with a lived experience, the same care and planning applies to all employees - Alex

This was a strong theme with many participants:

…the more I see from the peer [lived experience] workforce…the more I realise that the policies and procedure and support structures need to be in place for everybody, rather than simply just focusing in on the work of the peer workforce - Josh

Access to education and training

Much like equity across support and other policies some participants were adamant lived experience workers should have access to the same education and training as traditional workers:

…as far as training and skills enhancement, I think everyone needs the same thing, I don't think they [lived experience workers] *need anything special or different - Sarah*

Other participants agreed and elaborated, expressing a desire for service users to access to all the training traditional roles were exposed to:

I've always wanted our participants [service users] *as well as our peer* [lived experience] *workers to have the same training as we would - Tara*

Training was not just raised in relation to lived experience workers. Some participants were of the opinion traditional workers could benefit from learning lived experience skills:

… more and more of our workers who aren't employed to use their own story … maybe you know in reality everyone's using a bit of their story when they're working with consumer [service users] *and maybe just everyone* [people in traditional roles] *getting that training* [on how to use personal story effectively] *and framework would be useful - Bella*

Participants shared instances of training being provided by lived experience workers to people throughout their organisation:

…every new mental health clinician no matter what discipline - if they're medical to clinical, has to go through mandatory mental health orientation. So we [lived experience workers] *present at orientation and we present about recovery, we also present about consumer and carer services and explain what the different roles are so that there's an understanding that this* [lived experience] *service exists and what we do…we're now working with the mental health educators to embed lived experience in the annual mandatory training - Larry*

Lived experience devised Intentional Peer Support training was mentioned as providing structure to lived experience work, specifically the ability to sit with discomfort in relationships and in someone's recovery journey:

…if you are willing to demonstrate that you can sit in a really uncomfortable space, if you're able to show that others can sit in an uncomfortable space for a period of time too, I think it does influence the culture and there's a lot to do with intentional peer support - Jane

The Collaborative Recovery Model was also referred to as useful and inclusive:

…CRM the collaborative recovery model, is something that both peer [lived experience] *workers and normal* [traditional] *support workers could be involved in - Henrick*

Frameworks and approaches

In addition to training and education, participants raised appropriate frameworks and approaches as relevant both within organisations and within the lived experience roles.

Participants described the need for consistency in frameworks and theoretical underpinnings of working from a lived experience:

…we'll have 2 peer workers in a space who view recovery and lived experience journey really differently…there are so many different theoretical paradigms…and that can lead to immense tensions between those two workers around how things should be done…you know managers tear their hair out around that - Bruce

Other participants were also keen to see very clear structures, models and reporting lines sorted from an organisational perspective to benefit lived experience workers:

I want to get that model and structure and everything figured out, because I want to make sure that governance and those reporting lines and everything is concrete - Larry

While some participants disputed the need for organisational frameworks and cited the overarching 'human' approach as more integral to the work:

You don't need a framework to treat people with respect and dignity - Sam

Lived experience executive/senior manager Alex describes how her ideas around frameworks have changed over time:

…when I was a peer worker I had this really clearly defined idea of this is what it was [lived experience work] and this is how it should be and, this is what everyone should do…now I'm in this [executive/senior management] role, the more I doubt and challenge all those things and wonder more about situational flexibility within guidelines and…frameworks - Alex

Josh shared a similar story insisting on the same code of conduct for everyone, rather than a distinct code or procedure for lived experience workers:

there needs to be no two sets of policies and procedures or codes of conduct or any of that sort of stuff, we had a big battle here at the start about 'well we should have a code of conduct for peer [lived experience] *workers'. Well it should be our code of conduct for everybody - Josh*

Recruitment

Recruitment was seen by participants to be a critical part of organisational planning. Recruitment was discussed as a process that has been a learning curve and not always straightforward. It was stressed by many participants that recruitment involved much more than selecting people purely on the basis of their experience of mental health diagnosis:

The person has to be recruited for their skills and attributes and abilities to do the work first and their peer [lived] experience second - Josh

Larry described their recruitment processes becoming more refined as the organisation understood the demands of lived experience roles better:

…as we're recruiting new people we're asking more questions, we're a little bit smarter and it's something that you learn over time...It's always trial and error, we now know what the right questions are to ask people. In the past I don't know that we really asked people about if they understand what appropriate boundaries are, that's been a big issue - Bruce

In Josh's view the key was good communication skills and the ability to navigate complicated situations:

…recruitment processes that simply select people because of their lived experience…often putting those people in positions where they couldn't be successful, because the actual roles themselves do require a number of the softer skills, the more innate skills people would have when you're working in an environment where [it there is likely to be] complex communication and needing to go the extra yards, and some circumstances navigating through awkward, difficult communication scenarios - Josh

Some organisations were seeking applicants with previous experience in traditional roles in addition to their lived experience:

…over the last couple of months been talking to other services and other people that have used peer [lived experience] *support workers and their suggestions were that they prefer…somebody who's qualified to do mental health work, not just make lived experience the only qualification…what we're doing now with this round of recruitment is we're looking for case managers with experience working in mental health, that also have lived experience - Oscar*

Larry was also of the belief traditional mental health qualifications could be of benefit to lived experience workers:

…people who have been studying psychology or social work diploma or certificates, nursing, all of those kind of have some of the same skills underlying them and they're all about working with people and about caring for people and working with people to improve their lives…I think they [traditional qualifications] have a place - Larry

There were also issues in terms of attracting applicants. For some this was an historical rather than a current issue:

…we typically didn't get many applicants for the role so that was one of the struggles - Oscar

Risk of exposure to prejudicial attitudes as a result of their lived experience being publicly known proved a deterrent for some applicants:

…we've definitely had interviews peer [lived experience] support workers where we've brought up [need to identify as having a lived experience] in interview and people have then thought twice and withdrawn their application - Matt

Matt also expressed concern fear of public disclosure may make recruitment into senior lived experience roles more challenging if the service expands:

I think they [applicants] might perceive that in their career that would be a risk …is kind of un-closeting yourself in a way and that that there may be future impacts on their employment from a stigma perspective - Matt

However, this experience was not universal, many participants did not experience difficulty recruiting to lived experience roles:

I haven't had any problems, no. I've got people approaching us all the time to see if there's work here and I don't have work for them unfortunately – Sarah

Flexibility and accommodations

Many of the participants discussed the importance of supportive measures and ways to ensure sustainability for the lived experience workforce. This included a range of strategies from reasonable adjustments through to self-care. Both selective approaches tailored for the lived experience workforce and more universal measures were raised.

Some participants saw the responsibility for maintaining a safe environment for lived experience workers as belonging to employers:

…I think it's [an] *employer's responsibility to make anybody feel safe in the workplace and to get them to reach their full potential, that's what I think is a good manager and a good leader - Tara*

Others felt lived experience workers demonstrated a greater capacity to self-manage and to proactively care for their own wellbeing than traditional workers:

...the peers [lived experience workers] *are actually more proactive which I think is great because they know themselves and they know their limitations whereas sometimes some other staff* [in traditional roles] *think they're ok and they're not as attuned or aware of their own limitations - Sarah*

Lived experience executive/senior manager Sam was strongly in favour of formal reasonable adjustments or accommodations to allow for periods of un-wellness for members of the lived experience workforce:

the term reasonable adjustment - I allowed for a lot of allowances because of your illness, I didn't expect them [lived experience workers] *to be well all the time, I didn't expect them to not have blow ups every now and then, not become unwell and I've become passionate about reasonable adjustments - Sam*

However, Sam also acknowledged reasonable adjustments were not intended to over-protect or coddle the lived experience workforce:

I think we navigated the whole space around somehow initially differentiating if someone was not feeling great on a mental and wellness level and feeling we need to wrap some cotton wool around this [lived experience] *workforce - Sam*

For some participants there were tensions around the idea of reasonable adjustments and a view that perhaps reasonable accommodations or adjustments went too far:

someone with lived experience is allowed to potentially, get away with things probably isn't the right word, but is almost wrapped in cotton wool a little bit and not given appropriate feedback like any staff member would be - Reginald

Other participants saw reasonable adjustments or accommodation as a given as part of good staff management for any roles:

I think some of the stuff that people describe as reasonable accommodation it doesn't occur to me that it is. I think it's just managing people…lived experience workforce or otherwise - Matt

Lived experience executive/senior manager Alex, expressed an opinion that lived experience workers did not necessarily need specific accommodations different to other workers when the working environment was flexible and supportive:

…there is reasonable adjustment, we haven't had to use that a great deal or call on it a great deal, cos I think people feel fairly supported and in a flexible working environment anyway…I don't think any of us want to be wrapped in cotton wool and 'kiddied' through our roles, because that detracts from the roles - Alex

Flexibility was seen at times to extend to tasks and roles performed:

…some positions within the organisation where you know people can come and go, 'look I have some relative flexibility in my work and today I'm a bit shaky…and I'm probably not the number one person on the ground but this is a good day for me to catch up on this, that, or the other thing' which obviously is a little bit about kind of reasonable accommodation and some flexibility in the role - Matt

Sarah equates this flexibility to recovery orientated service provision and describes how this approach role models the ups and downs of recovery to service users:

...our [lived experience] *workforce is very comfortable coming forward and saying you know 'I'm not travelling very well at the moment I'm going to need to take some time off' and that's what recovery is like, I wouldn't expect my workforce to work any other way. I want them to be able to recognise if they're not travelling well, if they need that support, if they need to take time away so we're very flexible with that - Sarah*

Interestingly, despite the prevalence of flexible work arrangements, it was noted that high staff absenteeism was not seen as an issue within the lived experience workforce:

…we're pretty efficient, people take on the whole …considerably fewer than average sick days - Matt

Matt went on to share some strategies on how this was achieved in their organisation:

…we give everyone 5 weeks of holidays and then people have the option of buying an additional 3 weeks of holidays. So everybody if they want to can have up to 8 weeks…some of our [lived experience] *team were finding that when they had 4 weeks holidays…they were using it as restorative time and so not actually ever getting holiday time in there because it was really self-care time*

Some participants actively encouraged self-care and attention to work-life balance within the whole workforce:

…it's just fundamental that I readily talk about 'how you're going?' you know 'when are you taking leave?' 'When can you have a break?' 'Are your responsibilities taxing or are you doing - are you handling responsibilities ok?'…And the message I get back from people is that they value this workplace because there is flexibility and there is openness - Calvin

Calvin continued to explain some self-care strategies he encourages for all staff:

Encouraging people not to overwork, not to enslave themselves to a role, not to feel over responsible for their work or the agency. That's basically a message to everyone to self-care, whether they have their own articulated lived experience or not - Calvin

Burnout was not seen to be a particular issue for lived experience workers:

No I don't think [burnout is an issue] *it's really about encouraging people to look after themselves, encouraging people to come and see you if they're just feeling a bit off or a bit odd or something so that we can talk about what's happening - Sarah*

Tara shared this opinion and shared her belief that anyone can experience crisis or burnout:

Anybody can have those issues, anybody, anytime can have a crisis in their life that maybe puts them off kilter - Tara

Sarah considered the needs of staff with physical and mental health challenges were parallel and provided an example from her organisation:

You just need to get to know your staff and you need to understand their illness and be responsive to it…I have a staff member who has [a physical illness] *and it's very similar …at times they're enthusiastic and they're able to do their work really well but occasionally the* [symptoms of illness] *takes over and there's things that need to happen including bed rest and stuff like that. And that's no different to someone who maybe had an exacerbation in their depression or whatever, it's the same deal - they go home, we support them to have a break and then they come back - Sarah*

Organisational culture

In addition to challenges and structure, culture within the organisation was thought to impact significantly on the workplace experience for both lived workers and for managers.

Organisational culture and commitment

Participants described an emphasis on relationships and the role of the manager in setting the tone for the organisational culture:

…it has to be culture and it has to come from the board and the CEO down, that has to then filter down through regional managers, down through team leaders because I've had some long hard and quite difficult conversations with team leaders trying to get to change the culture in their team…you have to be the creator of the culture in your site and it has to be a healthy one based on knowledge and understanding of what peers [lived experience workers] *are and what peers aren't - Bruce*

Participants raised the need to prepare the workplace culturally for the inclusion of lived experience workers:

…part of the culture readiness stuff that should be in place. Organisations should be looking at how comfortable are we in us receiving feedback from a completely different perspective? How comfortable are we hearing maybe that we could do things differently? How able are we to have these difficult conversations? - Jane

Others discussed the value of addressing issues of power and hierarchy as part of addressing workplace culture:

The organisation's always been progressive…it's the culture of the organisation that's been really helpful it's interesting because we are quite centralised in terms of management but there's also a sense of a flattened hierarchy as well, especially in terms of the culture - Henrick

Some participants expressed their belief that the culture in their organisation was free from prejudicial attitudes:

…we're lucky here in this workplace where there is no discrimination and that our peer [lived experience] *workers are absolutely valued- Tara*

Different techniques were described to achieve positive organisational culture:

… I try and also develop or model servant leadership rather than top down dominant leadership so that's there's a culture hopefully of safety, so that we can then have in team meetings - when there's time to share, or in staff meetings when there's time to share, or when there's supervision and other conversations, people will feel a little more safe - Calvin

Calvin continued to describe the role of story sharing in creating positive workplace culture:

…encouraging story sharing is a key strategy and so it's honouring people's lived experience about their own vulnerability and their own pain. So our workers who are open to sharing story I will support them to do and I will publicly honour and make sure that people are clapped and affirmed- Calvin

Other participants described asking the workers to contribute their ongoing ideas about how to positively influence the culture of the organisation:

…needs to be the line managers that they're [lived experience workers] *working with and the people themselves and we actually mentioned to the* [other workers] *you know bring it up at your team meetings, talk about how this is going, because this is a learning process so how do we keep going with this and how do we do this together and we really sort of talked about how it could be supported ongoing for both of you – Bella*

Diversity in workforce and appreciating the benefits of diversity was considered important in creating a culture of tolerance and acceptance:

…we have a really cohesive team and we have people that aren't in peer positions that actually do have a lived experience and so the mixture of all of that means there's an accepting environment - Sarah

An important organisational factor cited was commitment from the organisation and this was expressed as a whole of organisational support:

I think it [lived experience workforce development] *takes organisational commitment, I think it takes whole of organisational commitment- Jane*

In Bruce's experience commitment was demonstrated through investment:

Oh they invested heavily in that role for that period of time and we got things going- Bruce

Influence of other staff

Organisational culture was also seen to be strongly influenced by the other staff and the degree of support and acceptance within teams. The degree of acceptance was deemed to be highly variable and dependent on individuals:

…culture has a lot to play with it…within the team here in [regional area] *there's, certainly would be mixed responses that would be a bit lukewarm, others would be actually quite excited about it* [lived experience work] *because they've read about it and it's very much ingrained in what we should be doing - Octavia*

Other participants agreed and elaborated to describe animosity from some traditional workers towards lived experience roles:

Not every mental health worker, and this astounds me, understands peers [lived experience roles]*, some get very resentful - Bruce*

The growth of the lived experience workforce was seen to contribute to this animosity:

…my personal opinion is that each discipline is really precious about their own discipline and that there's a place for every discipline and a need for every discipline in mental health services. [But] *there's no disputing there's not enough resources to have enough people across any discipline so when one workforce is growing it creates fear in the other workforces- Larry*

Larry continued to express a belief considerable change to existing attitudes would be needed to create workplace culture that was inclusive of lived experience and lived experience roles:

I think that probably there needs to be a lot more change in workplace stigma. A lot of clinicians aren't willing to admit their lived experience because of the perception that goes with that I suppose, so I think that there's still a little ways to go with culture - Larry

Conversely, in some organisations lived experience workers were seen to have contributed to a new level of openness and positively influenced the perception and acceptance of other staff to their own lived experiences:

So we're fortunate in that you know we can all share, we don't have to but we all feel comfortable if we share…they've [people in traditional roles] *all come out and said 'oh yeah I've had a bit of depression, I'm on medication' so I think that's awesome as well – Tara*

Senior roles for lived experience workers

A key factor in establishing best practice organisational culture was the employment of people with a lived experience in designated executive/senior management roles.

Josh described a person in a designated lived experience executive leadership role within his organisation who has been instrumental is shaping minds and culture:

We've sat in rooms and [senior lived experience colleague's] *on one side of the fence and everybody else is on the other side of the fence and we're going 'hang on a minute we need to work our way through this, and why is that' and we might have to come back to the second day or the third day or the fourth day and then people are starting to go 'well hang on a minute you know when you put it that way that's not what I was thinking the other day' and it's just like really digging through it day after day after day until we get it right…- Josh*

A number of the participants were employed in lived experience designated executive/senior management roles and described the importance of being present at executive level meetings:

So my role is a designated lived experience role …I have a personal lived experience with mental health, recovery from mental health issues of my own …our service in particular identified the importance of having someone with those values sitting on the executive team- Larry

Other participants held similar views and explained why it's so important to have lived experience roles at executive meetings:

…in health it's just all around clinical roles… that's why you know it's good having someone, me or whoever it is at the table saying 'well no let's think differently, let's use this funding for something else' - Alex

Executive/senior manager Larry concurred having the ability to speak at clinical governance and other key meetings provided opportunity to influence policy:

the main impacts I've seen are that there's a voice at the table now and that I'm able to sit there and challenge it… the policy was very paternalistic when it first was drafted and I had a voice at the table and was able to drive some minor changes …but previously there was not a voice at the table and my executive director even said if I had not've sat there and challenged that it wouldn't have changed, it would've been implemented the way it was so that's a really good positive outcome- Larry

Josh also raised the influence designated lived experience leadership roles have had in developing the frameworks and policies in his organisation:

And really it's about all of those peer work, lived experience type issues that come up so [senior lived experience colleague] *would obviously have her hand in all of our policies procedures, all of the types of methods and recruitment processes that we would use, even down to what sort of training and development we have on hand for people who have lived experience- Josh*

The value of senior lived experience workers as role models and mentors for newer lived experience workers was discussed:

…I think someone with that [lived] *experience in the workplace to be mentoring them* [lived experience workers] – *Octavia*

Trevor was of a similar opinion:

…it was certainly something that you know it was needed, to have a consumer [lived experience manager] managing consumers [lived experience workers]- Trevor

Lived experience executive/senior manager Sam shared his own experiences assisting newer lived experience workers*:*

I've been able to go in and spread the way for them [lived experience workers]- Sam

Larry also worked as a lived experience executive/senior manager and outlined further benefits to lived experience workers as a result of senior lived experience roles:

the key benefit for them [lived experience workers in less senior roles] *is they now have somebody who'd provided them with a voice. Previously from the feedback I've received …they had felt they were working very hard but not getting anywhere sometimes or that …their voice wasn't listened to because it wasn't valued …now I take their voice to the table our* [lived experience] *team is more*

motivated I believe and really grateful that executives have put my role in to play because we're making things happen now, we're seeing outcomes which is really exciting- Larry

Lived experience executive/senior manager Alex advocated for and promoted lived experience roles in the wider sector and across sectors as part of her job:

…part of my position description is to promote the value of the lived experience roles and how to challenge others on local collaborative boards and committees about that - Alex

Overall, senior roles for lived experience workers were thought to provide a statement that signals the importance of lived experience and raised the perceived value of lived experience workers within an organisation:

…some of it's about perception as well as making a statement- Trevor

Several organisations also raised he role of CCAG (carer-consumer advisory groups) as influencing organisational culture and bringing an independent lived experience voice to the table:

I think it's important to get a consumer advisory group, carer-consumer advisory group, which you know is that kind of touch point - Lilibeth

Prejudice and questioning designated roles

Often organisations referred to the need to tackle prejudicial attitudes in adopting a lived experience workforce and in merging this workforce within established organisations. Some participants described traditional mental health workers as main offenders in segregating or belittling people in lived experience roles:

…the reality exists that the people who work in the mental health sphere are in fact the worst culprits, mental health workers, community health workers, anybody who's in the know are the worst culprits for segregating and utilising the fact that someone has a mental illness to place them on a bar that's slightly lower than themselves and for a greater part of that is to make themselves feel better - Sam

Other participants raised the need to challenge these attitudes without becoming offenders and in turn segregating, 'othering' or belittling people in traditional mental health roles:

…and how do we challenge that respectfully but not militantly or without creating that 'othering' [of] *others* [traditional mental health workers] *which is often the lived experience - Alex*

In addressing discrimination and 'othering', some organisations have described tensions with not wanting to pigeonhole people or to create designated lived experience roles and to instead emphasise the shared aspects of the work, even questioning the need for 'labels':

…so in an ideal world I would prefer that we didn't have to label people peer workers…I think there's probably a raft of very good workers out there who don't particularly want to spend their day being called a peer [lived experience] *worker and don't particularly want to spend their day reciting their story or tell everybody that they had a mental health issue years ago or whatever that was so from my point of view the professionalization of the non-clinical workforce is the key, having qualifications in peer work certainly isn't a bad idea but I don't know whether necessarily creating a division between the peer worker and the non-peer worker or creating a broader division between the peer worker and the non peer worker is actually productive - Josh*

Others did not see that there was a significant distinction between roles:

…and people have emphasised the distinction between the roles [lived experience and traditional roles] *rather than they're parallel - Henrick*

Josh described a preferred future in which lived experience work would not need to be designated but added that we were not in that situation yet:

…'Why do we have to label people as peer [lived experience] *workers?' but we're not there yet and the world's not there yet, we have to label people as peer workers so that people don't get shortlisted out of recruitment processes because they've said they've had a mental health issue- Josh*

Josh continued, clarifying the current need for designated roles but emphasised that organisations needed to 'do the work' to understand and be prepared for lived experience roles and to ensure the roles were adequately supported:

…there is definitely a place for people with a lived experience to support other people with lived experiences…but it needs to be carefully looked at, it's not something that you can just be commenced with. It's a real depth of feeling from the organisation behind it, to the policies and procedures that support it and to the structures that support those people who have the lived experience – Josh

Recovery language and orientation

Senior managers described the underpinning recovery framework as an important foundation for the culture of the organisation. Lived experience workers were seen to promote recovery and contribute to a stronger organisational commitment to recovery orientation:

…having a service wide systematic strategic approach to recovery was one of the 2 priorities and I don't think it's just been having [lived experience consultant] *on board that's done that, but he's certainly had a significant contribution – Reginald*

Other participants described growing familiarity with the recovery framework as lending credibility to the lived experience workforce:

…there are people [in traditional roles] *that are becoming more exposed to recovery and lived experience that I think that is changing some of those thoughts around the credibility of lived experience versus clinical - Octavia*

Some participants outlined initiatives to increase the level of recovery engagement amongst staff:

…we want to do local recovery champions at the [name of service] *facilities that we award at their staff forums, and then we want to do an annual overall recovery champion …we have staff forums all the time - they doing awards for best nurse, best doctor whatever …So it's part about recognising people who are doing really good work but also again it leads into changing culture and what is recovery and why people are being rewarded for that - Larry*

Managers further identified that peer workers were viewed as the barometer of recovery and helped hold an organisation accountable in their practice and language:

…this is the function of peer support [lived experience work] *so you know it is this person's job to make sure we've got you know consistent* [recovery focused] *language and that if they hear anything*

and it doesn't sound like the correct sort of language we should be using, it's their job to talk to the team about it - Oscar

Another participant reflected on how having people with an acknowledged lived experience in the team inspired more thoughtful use of language, ultimately leading to a more inclusive workplace and service:

50% of my colleagues here often have a mental health issue, it's only when that starts to happen that you start to seriously consider minding your language, seriously considering your own thoughts about people who have mental health issues, seriously consider all of those barriers that are the stigma – Alex

Cultural fit and rural/regional experiences

A lived experience workforce was not seen as a 'one model fits all' and many nuances were recognised in appreciating the role of the culture of the organisation as well as the local culture and community.

Some participants emphasised the need for lived experience workers to fit within the existing culture of the organisation:

…they've gotta be a cultural fit for our organisation - Larry

The influence of lived experience workers on culture was considered by some to be particularly relevant in isolated communities:

…because of their lived experience that's why they're employed…it's great for the company because there's a lot of people in isolated communities out there that haven't ever met with somebody that's actually a [lived experience] *worker that has experienced some things in their life so I think it's fantastic - Bella*

For other participants they saw additional challenges for lived experience workers in rural and regional settings:

I think it would be culture I come from a small a town, I think that smaller communities have a lot more challenges than probably some of the bigger metropolitan cities, and they don't value it because the [lived experience] *workforce is very small there might only be 1 person actually driving the whole agenda and I imagine that that would be incredibly isolating - Larry*

Jane agreed and raised the need for Indigenous specific lived experience roles within Indigenous communities:

…some peers [lived experience workers] *didn't even know there were other peer workers, they might be the only peer worker employed by the organisation and particularly when some people are working in communities like* [local community-name removed] *they might be an Indigenous peer worker- Jane*

Previous history with lived experience workers

Previous experiences with lived experience workers had influenced the views of some participants regarding the effectiveness of lived experience workers within an organisation. These experiences were sometimes varied:

…so we had a number of people at different sites and we had various degrees of success with peers [lived experience workers] *being able to come on board, stay on board, and not have long periods of time of un-wellness - Bruce*

Oscar also described retention as an issue at earlier stages of their program:

when I first took over [support program] *…we had a lot of trouble keeping anyone in the peer* [lived experience] *support role for any sort of extended period, like we had 4 or 5 workers and they'd last on average maybe 6 months- Oscar*

Some participants explained how poor recruitment of one lived experience role could lend support to the idea that all lived experience roles are limited:

if we recruit a peer worker…simply because they have a lived experience and they don't have the communication skills, they don't have the attitude, they don't have the temperament, they don't have the personality to be able to engage with people who also have lived experience, then suddenly for the naysayers and the stigmatisers that can often develop into a little bit of a smug 'well I told you so' - Byron

Future focus and emerging policy

The Perceived Value and Understanding of the Role in conjunction with the Role of Executive/Senior Management and consequently Organisational Factors, all directly influenced the final major category - Future Focus and Emerging Policy.

Emerging policy/ National Disability Insurance Scheme

Emerging Policy was considered as essential to driving future practice. Significant changes to practice were particularly anticipated as a result of the National Disability Insurance Scheme (NDIS):

… the other big transition and a lot of the work that's going on at the moment is, is preparing for the NDIS …a lot of changes are undergoing because of the NDIS and the changes to block funding for personal budgets - Hendrik

Potential avenues for growing the lived experience workforce were identified as a result of the NDIS:

I see that potentially we will have a whole lot more people requiring mental health support. Under that scheme [NDIS] *and if it's needed to make a better connection or peer* [lived experience] *support could form part of the package that somebody gets - Byron*

Other participants held less optimistic views:

The NDIS is going to kill peer [lived experience] *work. I have no question in my mind about that. There is no capacity in the funding to support peer workers, there's no capacity for them to take time off, if they're not there, they're not gonna get paid. We get the 42 dollars an hour from the NDIS to*

provide support - we don't get any money for transport, we don't get any money for conferences or skilling people up, we don't get any money just to do group team activities to keep the team happy and healthy - Sarah

Sarah continued to express her concerns that lived experience roles would not be funded through the NDIS regardless of whether public interest in accessing lived experience assistance grew as a result of choices service users are expected to have under the scheme:

…people that are asking for peer [lived experience] *workers in their package that's great, but that doesn't attract any more money…I just worry that the things that we've created here the things that support peer workers is not funded in the NDIS- Sarah*

Future expansion within organisation

Participants shared visions of future growth within their organisation:

Now we're just working at strengthening, integrating and growing the [lived experience] *workforce…we're in the process this year of doing a lot of planning around our workforce. We're looking at what FTE* [full time equivalent positions] *we have…we're also looking at the clinical services plan for mental health in general and looking at all the models that we have and looking at if there is a 5-year plan – Larry*

Josh's organisation intends to expand the presence of lived experience workers across additional programs:

…certainly looking at having peer [lived experience] *workers in every program that we have and we're working towards that*

The successful employment of lived experience workers was seen to create momentum for further growth:

Once you get started it [creating a lived experience workforce] *gets easier…has its own momentum, whereas starting in that space there are challenges with it…you might give that a go and go 'oh you know this is really hard'. It's just a resource intensive thing to introduce any new thing into your workspace - Tara*

Future growth was process driven and involved consultation and feedback both internally and externally:

…the role with the advisory partners is to get feedback and check in - what's working, what are the other possibilities and any decisions that we'd like to make…there's also people [with a lived experience] *that we would check in with and contact just to get a feel for 'we're thinking this, how do you think that might fit with you'…and I think that should be a part of practice anyway…anyone can do that* [provide feedback and advice]*, it's not particular people are chosen. We invite anybody that's accessing our service and they can all be a part of it - Jane*

Motivation to expand the lived experience workforce was partly attributed to 'healthy competition' between services:

So the 3 services that make up [metropolitan health service] *we've got 3 catchment areas. So if one of the 3 services starts a consumer or carer project, it seems to work very quickly - the others adopting it. Because as I say, the competition 'well they're doing it so why aren't we doing it' …you know healthy competition is, it's something that we've found has worked very well – Trevor*

Reginald held similar views:

when there is another service that you can easily benchmark against and you see what they're doing and you go 'wow is that something that we could do over here' …I'm all for it

In addition to services changing and embracing lived experience, the lived experience workforce was also viewed as evolving. Penny noted that the workforce was now more highly skilled and clear in their use of 'lived experience':

so they're [current lived experience workforce] *kind of a second generation of workforce- Penny*

Future expansion in mental health and beyond

Participants described a vision of the lived experience workforce that extended beyond their individual organisation and reaching across the mental health sector:

I would hope that our sector continues to honour and affirm and welcome lived experience roles… because we know…that local [lived experience] *knowledge is just so powerful and so people who are feeling isolated or excluded or vulnerable have a* [lived experience] *worker with them or someone alongside them who maybe hasn't had the* [exact] *same experience and pain but who can identify somewhat or share a story about 'hey I've been in a carers role' or 'this is what I negotiate with my psychiatrist' - Sarah*

Alex held a similar opinion:

I see great opportunities for services of this kind [lived experience service]- *Alex*

In addition to the extended scope of lived experience roles across the mental health sector. Some participants expressed their belief in the potential of lived experience workers beyond mental health:

I see the potential for them to be in any sector I think they bring a wealth of education and different perspectives on life – Tara

Tara continued, situating lived experience work within the political context of social and attitudinal change and raising the need for lived experience credibility within the broader community:

…I see the value in it [lived experience perspective] *across everything and every part of the community…if we can educate the community then I believe we can break down that stigma of mental health challenges…I have a plan for this region that's for sure …they're credible in their lived experience, but that's not recognised I don't think in the broader community – Tara*

Some participants were of the opinion that many developments were yet to come:

I think exciting times ahead - Lilibeth

Discussion

Leadership role for executive/senior management

The overarching theme of this research was the role of executive and senior management in translating ideas and values to action. Participants within organisations with developed lived experience workforces had either demonstrated leadership themselves or described others in executive/senior management roles demonstrating leadership to enable this development. Equally, a lack of leadership and/or commitment from executive/senior management was viewed by participants as one of the most significant barriers to the development of lived experience workforce.

Executive/senior management provide leadership

Commitment to lived experience workforce increased with greater investment

Risks and effort is seen as worthwhile

Overarching message from those who have committed to lived experience, 'just do it'

Participants who had been involved in the development of lived experience roles shared stories that were often fraught with challenges, false starts and examples of 'mistakes'. However, these participants described the process as one of learning rather than failure. Despite mistakes and challenges, none regretted the decision to employ and support lived experience workers. Instead these participants also described their commitment and their perception of the value of lived experience roles growing over time. Many also offered ideas and practical support to organisations looking at starting or, growing a lived experience workforce. These participants were passionate about the need to share their learning so others could benefit, and to actively promote lived experience work throughout the sector to increase perceived value and understanding.

As explained by participants, success was often preceded by a willingness to invest, take risks and be innovative. However, participants also recognised that it does take time and commitment to introduce a new discipline into the organisation and to manage change

successfully. For lived experience roles - often identified as 'change agents' [15] there could potentially be clashes between lived experience ideology and pre-existing work culture and beliefs [16]. As the findings demonstrate, to truly embrace the benefits of lived experience work, organisations need to address a range of issues. This often includes changing workplace culture, which may require significant re-training and education across the whole organisation [17]. Organisations willing to make this commitment to lived experience work could arguably also be said to demonstrate a commitment to broader mental health service reform, particularly in moving towards the recovery approach due to the well accepted role of lived experience in meaningful recovery implementation [18].

Speculation versus experience

From early in the interview process significant differences were noted between the responses of participants who did have experience managing lived experience workers, as opposed to those who did not. Participants who had limited or no experience managing people in designated roles, by necessity had to speculate on what it might be like to manage lived experience workers. Of interest, participants with low or no first-hand experience of lived experience workers were much more likely to express negative views in relation to lived experience workers, compared to participants with greater hands-on experience. One salient example of this was concern about burnout, which was raised by a few participants who held limited or no experience managing lived experience workers. These participants speculated that lived experience workers may be more likely to burn out and/or prove susceptible to being traumatized by their work than staff in traditional roles. Conversely, those participants experienced at managing people in lived experience roles, expressed the belief burnout was no more an issue for lived experience workers than other roles. Of significance, these participants were of the opinion lived experience workers typically demonstrated high levels of resilience and were more likely to have insight and seek support when needed than staff in traditional roles. Of note, those participants who had managed lived experience workers tended to be adamant and often irritated by the assumption lived experience workers were more vulnerable than other workers.

> The more exposure people had to lived experience roles, the more highly they valued them

Previous negative experiences with lived experience roles

Some participants discussed the challenges when an organisation or individual had a previous 'negative' experience employing a lived experience worker. For those disinclined to value lived experience, this was seen as a confirmation of their beliefs about the workforce as a whole. For others with greater interest in the potential of lived experience, it was generally attributed to poor recruitment methods, including a lack of understanding of what to ask at interview, 'tokenistic' recruitment to the roles and/or, flawed position descriptions. Refining recruitment methods over time was raised by many participants. Recent research also confirms the need for better role clarity and definition of lived experience positions [19], to maximise the many benefits of the roles.

Negative experiences were often the result of flawed recruitment process and/or poor role clarity

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
- service users

The ability of lived experience workers to build authentic, empathetic relationships with service users, which facilitated and supported recovery, were often described throughout the study. The abilities of lived experience workers to engender trust and build rapport were also frequently cited. Participants described lived experience roles as being uniquely focused on the needs of the service user and their journey. Significantly, they were viewed as a living example of hope and recovery.

Lived experience workers were seen to provide more equitable relationships, helping to address power imbalances between service users and traditional roles. The ability for people in lived experience roles to respectfully challenge service users was likewise viewed as a unique skill and benefit. The lived experience discipline of 'Intentional Peer Support'

describes mutuality between lived experience workers and service users as a means of shifting beyond limiting views people with a lived experience can have of themselves as a result of diagnosis and service use [20].

Lived experience workers promoted and provided: empathy, hope, equality, trust, connection, understanding, education and positive workplace culture

The lived experience role in contributing to positive workplace culture and enacting systemic change was noted in several areas. Other benefits to organisations and colleagues in traditional roles included provision of recovery training, better recovery orientation within organisations and providing a 'bridge' between service users and traditional workers [21].

Overwhelmingly, those with hands-on experience of lived experience workers in their organisation were more likely to be convinced of the value of lived experience roles. Again, those with limited or no experience were, perhaps unsurprisingly, less likely to articulate the value.

Understanding and supporting the uniqueness of lived experience

Nearly all participants unequivocally confirmed they saw some value in lived experience roles. In addition, executive/senior managers who employed lived experienced workers also spoke repeatedly of the uniqueness of the roles. Importantly these participants articulated lived experience roles more clearly, particularly in relation to use of lived experience, and why it was effective in assisting others. In these cases, protecting and emphasising the uniqueness of the roles was often reinforced through lived experience supervision and reflective practice. Other participants grappled to understand the nature of lived experience work. Many participants either didn't perceive noteworthy difference, or viewed lived experience workers as having the same skills as other workers and 'something extra', but often struggled to define what the extra ingredient was. This lack of clarity was noted as a barrier, with some participants seeing the potential for the roles to be co-opted by

dominant ways of working and thinking, if the uniqueness was not understood and valued. This reflects clear themes in the literature regarding the need for the uniqueness of lived experience roles to be preserved [4].

Lack of understanding/clarity of roles creates risks for lived experience roles

Exposure increases understanding of the unique roles

Action is then taken to preserve that uniqueness

From fear to understanding

Contention existed around the need for an identified or designated lived experience role. Some participants questioned how lived experience could be accurately defined, while others suggested in an ideal world labels wouldn't be necessary – instead we could instead draw on universal struggles and shared humanity. However, some participants argued that designated roles needed to be prioritised as acknowledging having a lived experience was otherwise still likely to result in a reduction of employment opportunities [22].

Participants expressed the opinion fear and discrimination towards people with lived experience is still prevalent in some mental health services and needs to be challenged. Contemporary literature supports the notion traditional workers can be fearful of and discriminate against both lived experience workers [23] and service users [24].

Whilst people with lived experience are often still marginalised and discriminated against within the community, research shows that as exposure to people who are 'out' with their lived experience increases, the level of understanding, empathy and shared journeys subsequently increases [22].

Just by being there in designated roles, lived experience workers challenge prejudicial attitudes and are positively changing the culture of services

Similarly, participants explained how exposure to lived experience workers had changed their views of people with lived experience. Participants also described organisational policy, direction and the assumptions and attitudes of other staff changing in positive ways.

Having designated lived experience roles in the workplace was seen to increase understanding and alleviate the fear, assumptions and myths surrounding people with lived experience [25]. Perhaps more importantly, exposure to lived experience workers has been found to encourage greater understanding and empathy towards people accessing services [26].

Champions

The role of champions was considered particularly important due to the contrast between lived experience and traditional ways of working, the need to embrace organisational/workforce change, and a lack of understanding of lived experience work generally.

> Champions actively promote and advocate for lived experience, ensuring meaningful input

Champions were seen to use their positions of authority to actively advocate and campaign for lived experience roles. The willingness of champions to share or transfer power in relevant areas has also been reported in previous studies [27].

Champions or allies are seen to work in true collaboration with people in lived experience roles, creating opportunities for meaningful input and ensuring the unique knowledge and expertise of lived experience is given equal weighting to allow for impact [28].

Senior roles for lived experience

The inclusion of lived experience within executive/senior management was seen to provide unique opportunities for cultural and organisational change and impact that would not otherwise occur, due to their position in the organisation and presence at governance and

other key meetings. Throughout the mental health sector the creation of such roles has led to significant priority given to lived experience workforce development, and in some cases, substantial increase in designated lived experience roles [29].

Lived experience in senior or executive roles creates opportunities for impact and significant cultural and organisational change

Frameworks and professionalisation of the roles

Some participants, including very clear champions of lived experience workers, thought that some guidelines or structure were necessary for accountability and credibility. However, the perception of lived experience being governed by less rules or guidelines in comparison with traditional roles was seen by many as a strength in supporting service user driven recovery.

The question of professionalisation for the lived experience workforce was raised in terms of legitimising and supporting the development of the role. Professionalisation was seen 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. Professionalisation was referred to by participants in relation to professional behaviour and conduct, being seen as a 'profession' and training and qualifications.

In a best case scenario, qualifications were seen to affirm and add to the role. However, the first available accreditation – the Certificate IV in Mental Health Peer Week, received lukewarm feedback from participants, with most seeing it as more useful for advancing the security of lived experience roles than aiding skill development.

Some participants mentioned training that was seen to provide more specific skill development. However the lack of, and need for, overarching theoretical frameworks to base wide-scale training on was also raised [30].

To maintain the unique benefits of lived experience involvement, the roles need to be recognised and enabled to utilise their unique skills and knowledge [31], regardless of whether those skills are gained 'incidentally' in their own life and recovery journey, or

through formal training. However, participants across the board were clear that lived experience alone did not comprise that unique knowledge. A range of skills were described including; appropriate, judicious use of personal story; highly effective interpersonal/communication skills; ability to sit with discomfort; ability to navigate complex systems and emotional situations.

A few participants referred to traditional mental health qualifications as desirable or transferable. This is assertion is debateable considering the uniqueness of lived experience perspective, how different it is from that of traditional roles and the risk of roles being further co-opted as a result of conflicting or contradictory viewpoints [32].

Reasonable accommodations

Reasonable accommodations were variously seen by different participants as; necessary; not necessary in a workplace that emphasised flexibility and; potentially treating lived experience workers preferentially.

While some saw what they viewed as potential for absenteeism and unreliability as poor role modelling from lived experience roles, other participants, typically with more hands-on experience managing lived experience workers, saw lived experience workers as good roles models both for recovery and hope in general [9]. People in lived experience roles not always being completely 'together' or not pretending to always be completely together, was seen to provide an accurate example of the ups and downs of recovery and make it seem achievable to those accessing services.

Whole-of-service approach

The need for a whole of service approach was frequently raised by participants in relation to a number of issues including workplace culture, policies, equitable structures, access to training and education, and support and flexibility.

A whole of service approach and positive workplace culture with an emphasis on flexibility, contributes to the success of lived experience roles

Workplace culture played an important role in setting the tone for an integrated and respected lived experience workforce. The workplace culture within organisations was developed both informally though open communication, and more formally through processes and policies. Participants referred to policies as providing as a way of cementing the value and understanding of lived experience roles within the organisation. Policies were either specific to lived experience workers or developed so they were inclusive and supportive of both lived experience and more traditional roles.

Equitable structures likewise provided scaffolding so lived experience workers would have opportunities for mobility within their employment and would not be restricted by a 'glass ceiling'. Work stability and security was further enhanced through access to training that recognised and made an investment in the professional development of lived experience workers.

Participants repeatedly acknowledged the role of supervision and support in effectively sustaining lived experience workers, guarding against burn out and as a platform to reflect on the nature of lived experience work, including potential challenges.

Recommendations

Recommendation 1.1

Engender greater understanding of the value, uniqueness and benefits of lived experience roles for executive/senior management across the mental health sector and beyond via:

- Training and education
- Networks, including other organisations with significant experience employing lived experience roles, and lived experience leaders/networks
- Exposure to lived experience work – including site visits to other organisations with lived experience workers and, where possible, host visits from lived experience workers.

Recommendation 1.2

Provide a learning platform where organisations with success and experience employing lived experience workers can share their knowledge and support organisations planning to employ lived experience workers.

Recommendation 1.3

Champion lived experience work in appropriate forums, articulating the uniqueness and value of the roles.

Recommendation 2.1

Ensure adequate resources are available and meaningful planning has been undertaken. Find ways to prioritise lived experience workforce development if not already a priority.

Recommendation 2.2

Be prepared to invest and commit, with an acknowledgement that change takes time, risk and innovation.

Recommendation 3.1

Identify the vision for lived experience roles and share it. Clearly articulate the vision within the organisation and pro-actively work towards buy-in from all staff.

Recommendation 3.2

Develop a whole of organisation approach, including policies and processes that are relevant and inclusive of the work of lived experience and adopt that approach throughout the organisation.

Recommendation 3.3

Establish or adopt a framework for lived experience workers that can be adapted to the specific context and culture of the organisation to allow lived experience workers to maintain the flexibility of their roles and provide optimum support to service users while also maintaining accountability and credibility.

Recommendation 4.1

The uniqueness of the roles needs to be understood and reflected within the position description.

Recommendation 4.2

Where the role is not sufficiently understood, assistance is sought through relevant networks including other organisations with greater experience/success and lived experience leaders/networks and research.

Recommendation 5.1

Invest in the lived experience workforce and create opportunities for professional development and career progression including training and qualifications.

Recommendation 5.2

Create designated lived experience executive/senior management positions to allow for more meaningful inclusion of lived experience perspectives and greater impact within the organisation.

Recommendation 5.3

Provide opportunities for lived experience supervision and/or ongoing reflective practice for lived experience workers, with management and other lived experience workers.

References

1. Byrne, L., et al., *Things you can't learn from books: Teaching recovery from a lived experience perspective.* International Journal of Mental Health Nursing, 2013. 22: p. 195-204.
2. Trachtenberg, M., et al., *Peer support in mental health care: Is it good value for money?* 2013, Centre for Mental Health: London.
3. Moran, G.S., et al., *Benefits and mechanisms of recovery among peer providers with psychiatric illnesses.* Qualitative Health Research, 2012. 22(3): p. 304-319.
4. Moran, G.S., et al., *Challenges experienced by paid peer providers in mental health recovery: A qualitative study.* Community Mental Health Journal, 2013. 49: p. 281-291.
5. Happell, B., *Polarisation and political correctness: Subtle barriers to consumer participation in mental health services.* Australian e-Journal for the Advancement of Mental Health, 2008. 7(3): p. 1-7.
6. Bradstreet, S. and R. Pratt, *Developing peer support worker roles: Reflecting on experiences in Scotland.* Mental Health and Social Inclusion, 2010. 14(3): p. 36-41.
7. Bennetts, W., et al., *Real lives, real jobs: Sustaining consumer perspective work in the mental health sector.* Advances in Mental Health, 2013. 11(3): p. 313-326.
8. Kern, R.S., et al., *A demonstration project involving peers as providers of evidence-based, supported employment services.* Psychiatric Rehabilitation Journal, 2013. 36(2): p. 99-107.
9. Franke, C.C.D., B.C. Paton, and L.J. Gassner, *Implementing mental health peer support: A South Australian experience.* Australian Journal of Primary Health, 2010. 16(2): p. 179-186.
10. Nestor, P. and C. Galletly, *The employment of consumers in mental health services: Politically correct tokenism or genuinely useful?* Australasian Psychiatry, 2008. 16(5): p. 344-347.
11. Charmaz, K., *Grounded theory in the 21st century*, in *The sage handbook of qualitative research*, N.K. Denzin and Y.S. Lincoln, Editors. 2005, Sage Publications: Thousand Oaks: London: New Delhi.
12. Corbin, J. and A. Strauss, *Basics of qualitative research: Grounded theory procedures and techniques*. 3rd ed. 2008, Newbury Park: London: New Delhi: Sage Publications.
13. Birks, M. and J. Mills, *Grounded theory: A practical guide*. 2011, London: Sage Publications.
14. Strauss, A. and J. Corbin, *Basics of qualitative research: Grounded theory procedures and techniques*. 2nd ed. 1990, Newbury Park: London: New Delhi: Sage Publications.
15. National Mental Health Consumer and Carer Forum, *Supporting and developing the consumer and carer identified workforce - a strategic approach to recovery*. 2010, National Mental Health Consumer and Carer Forum: Canberra.
16. Byrne, L., B. Happell, and K. Reid-Searl, *Lived experience practitioners and the medical model: World's colliding?* Journal of Mental Health, 2016. 25(3): p. 217-223.
17. Basset, T., et al., *Lived experience leading the way: Peer support in mental health*. 2010, Together UK: London.
18. Ochocka, J., et al., *A longitudinal study of mental health consumer/survivor initiatives: Part 3-a qualitative study of impacts of participation on new members.* Journal of Community Psychology, 2006. 34(3): p. 273-283.
19. Cronise, R., et al., *The peer support workforce: Results of a national survey.* Psychiatric Rehabilitation Journal, 2016. 39(3): p. 211-221.
20. Mead, S. and C. MacNeil, *Peer support: What makes it unique?* International Journal of Psychosocial Rehabilitation, 2006. 10(2): p. 29-37.
21. Loumpa, V., *Promoting recovery through peer support: Possibilities for social work practice.* Social Work in Health Care, 2012. 51(1): p. 53-65.
22. Rüsch, N., et al., *Efficacy of coming out proud to reduce stigma's impact among people with mental illness: Pilot randomised controlled trial.* The British Journal of Psychiatry, 2014(204): p. 391-397.

23. Happell, B., et al., *Lived experience in teaching mental health nursing: Issues of fear and power.* International Journal of Mental Health Nursing, 2015. 24: p. 19-27.
24. Sweeney, A., et al., *The role of fear in mental health service users' experiences: A qualitative exploration, social psychiatry and psychiatric. .* Social Psychiatry & Psychiatric Epidemiology, 2015. 50: p. 1079 -1087
25. Michaels, P., et al., *Changing stigma through a consumer-based stigma reduction program.* Community Mental Health Journal, 2014. 50(4): p. 395-401.
26. Ilic, M., et al., *Belittled, avoided, ignored, denied: Assessing forms and consequences of stigma experiences of people with mental illness.* Basic and Applied Social Psychology, 2013. 35(1): p. 31-40.
27. Baldwin, M. and J. Sadd, *Allies with attitude! Service users, academics and social service agency staff learning how to share power in running social work education courses.* Social Work Education, 2006. 25: p. 348-359.
28. Perkins, R. and M. Slade, *Recovery in England: Transforming statutory services?* International Review of Psychiatry, 2012. 24(1): p. 29 - 39.
29. Jackson, F. and T. Fong, *Why not a peer worker.* Mental Health and Social Inclusion, 2017. 21(3).
30. Davidson, L., et al., *Peer support among persons with severe mental illnesses: A review of evidence and experience.* World Psychiatry, 2012. 11(2): p. 123-128.
31. Repper, J. and T. Carter, *Using personal experience to support others with similar difficulties: A review of the literature on peer support in mental health services*. 2010, Together, University of Nottingham, NSUN.: London.
32. Byrne, L., B. Happell, and K. Reid-Searl, *Recovery as a lived experience discipline: A grounded theory study.* Issues in Mental Health Nursing, 2015. 36(12): p. 935-943.

Appendix

Appendix 1. Chief Executive Officer letter of approval

CEO name
And
Address

Dear _____,

There is an increasing trend to employ 'lived experience' (LE) mental health workers around much of the developed world. LE workers are people who have recovered from mental illness and use their experience of the mental health system to help others better negotiate their journey. Common roles for LE workers include; peer support, consultancy and companion activities. LE workers provide a very useful and cost-effective effective adjunct to traditional treatment.

Despite the demonstrated benefits of LE workers, Australia is facing some challenges including LE roles within the wider health care workforce. To better understand the issues around LE workers, we are conducting research on how best to integrate LE workers into the health care system. Because managers within the health care sector are an important group of stakeholders in this discussion, we are very interested in their views on the use of LE workers.

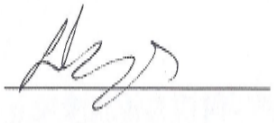
The goal of this research is to find out what senior managers in the health care sector consider critical issues around

- The deployment of LE workers,
- how we might better articulate the role of LE workers
- how we might integrate LE workers within the workforce options available to mental health care providers.

We would like permission from your organisation to contact employees and to invite them to participate. All participation will be entirely voluntary and we are seeking individual opinions, not the perspective of the organisation. All participation will be confidential and all identifiers will be removed in reporting. The time commitment will be small and typically involve a ninety minute focus group or sixty minute conversation either in person or by phone.

We have received ethical approval from CQUniversity H15/11-262, and Qld Health HREC/16/QPCH/298. Before we can approach mental health workers, our Ethics Committee has requested that we seek organisational approval to approach your staff. If you happy for us to approach the employees of your organisation and invite them to participate in this research, please indicate your organisational support by signing the section below and returning it to: **Dr Louise Byrne, c/o CQUniversity Rockhampton, Building 18, Bruce Highway, North Rockhampton, QLD** or to my email account at l.byrne@cqu.edu.au

Kind regards



Dr Louise Byrne
Central Queensland University, Rockhampton, Qld 4702
If at any time you have any concerns or questions, please feel free to contact me on 0401056583

Permission to Undertake Research

I, _____(insert name)

as the designated signatory for

_____(insert name of organisation)

consent to employees being approached in order to participate in the research project titled,

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

Signed _____

Date _____

Please sign and return to: Dr Louise Byrne, c/o CQUniversity Rockhampton, Building 18, Bruce Highway, North Rockhampton, QLD or by email account at l.byrne@cqu.edu.au

Appendix 2: Copy of email to invite participation

We are writing to you in your capacity as a senior manager or other relevant employee of a mental health service delivery organisation.

We would like you to invite you to participate in either an interview or focus group to explore the barriers and enablers for lived experience roles in the mental health sector.

This research aims to:
1. Understand the perspectives of senior managers of mental health services regarding the barriers and enablers for lived experience workers within the mental health sector
2. Discover new methods of effectively integrating lived experience roles into the wider workforce.
In addition to the focus group, a limited number of individual interviews will also be conducted.

To register your interest in the focus group or individual interview, please send an email to Dr Louise Byrne, Lecturer at CQUniversity Australia, l.byrne@cqu.edu.au

Project brief:
Lived experience roles in this case include all roles where the person is employed to work specifically from their lived experience of mental illness and recovery including; peer workers, consumer consultants, consumer companions and others.
Lived experience roles have grown considerably in recent years with further expansion anticipated. Research identifies that issues exist in relation to the successful integration of lived experience roles within organisations and workforce development is needed.
Senior management of mental health services have been identified as crucial to the success of lived experience workers due to their role in defining and shaping

workplace culture and their understanding of successful work collaboration. However the perspectives of senior managers is currently not well represented. Your valuable perspective will assist to inform the development of a toolkit for the integration of lived experience workers into the wider mental health workforce. With the ultimate aim of contributing to more inclusive workplace culture and more effective lived experience roles.

A copy of the information sheet is attached, as is the consent form.

Appendix 3: Information sheet

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

INFORMATION SHEET

Project Overview

'Lived experience workers' in this case include all roles where the person is employed to work specifically from their lived experience of mental illness and recovery including; peer workers, consumer consultants, consumer companions and others.

Lived experience roles have grown considerably in recent years with further expansion anticipated. Research identifies that issues exist in relation to the successful integration of lived experience roles within organisations and workforce development is needed.

Senior management of mental health services have been identified as crucial to the success of lived experience workers due to their role in defining and shaping workplace culture and their understanding of successful work collaboration. However the perspectives of senior managers are currently not well represented.

Your valuable perspective will assist to inform the development of a toolkit for the integration of lived experience workers into the wider mental health workforce. With the ultimate aim of contributing to more inclusive workplace culture and more effective lived experience roles.

Participation Procedure

If interested in participating, you will be asked to fill in a demographic questionnaire. This will enable a broad range of senior managers to be consulted. The selection process is explained on the demographic questionnaire which will be sent to you in the initial email.

If you choose to participate and fall within the eligibility criteria, you will be asked to attend a focus group or one-on one interview.

The focus group will include 12 participants. The researcher will begin with a few broad questions and tailor questioning to explore themes that emerge. The focus group is expected to take approximately 90 minutes.

A select number of participants (6-15) will be asked to participate in an in-depth interview to further identify the enablers and barriers to lived experience work. Guidance will also be sought on how to successfully integrate lived experience roles into the wider workforce. The interview is expected to take approximately one hour.

Both focus group and interviews will be audio recorded. You will be asked to provide written consent for the recording to occur prior to the interview.

The opportunity to explore issues arising in interviews may be requested. You will be under no obligation whatsoever to do so. Any follow-up interview would also be recorded and written consent would again be required.

Benefits and Risks

The research focuses on the integration of lived experience workers, and it is not envisaged that this would result in any risks outside of that faced in everyday work situations. In the unlikely event that during interviews you feel uncomfortable, or anxious about your participation, please alert the interviewer, and the interview will cease.

Should any issue arise as a result of your participation in this research, support is freely available and you will be advised of appropriate counselling or follow-up by the interviewer.

Confidentiality / Anonymity

If you choose to participate your confidentiality will be preserved. You will be asked to record your name on the demographic questionnaires only to facilitate the selection process. No information that identifies you will be made public. In the reporting process, quotes or information that could potentially identify participants, organisations or districts will not be used.

Outcome / Publication of Results

Findings from this research will be published in scientific journals or other relevant publications. Findings may be presented at research conferences. It will not be possible to identify any individual participant as a result of publication or presentation of these findings.

Consent

If you participate in the recorded focus group or interview, consent will be obtained by completion of a signed Informed Consent form (enclosed).

Right to Withdraw

You have the right to withdraw from this study at any time, and can do so without prejudice or penalty.

Feedback

Participants will have the option of being provided with a Plain English statement of results at the conclusion of this study, when completing the Informed Consent form. Alternatively, participants may request to be provided with a copy of this statement at any time during or after the study by contacting the research team using the details provided below. It will not be possible to identify any individual participant as a result of publication of this statement.

Questions / Further Information

Please contact the researchers:

Dr Louise Byrne

School of Nursing and Midwifery, Higher Education Division, CQUniversity, Rockhampton QLD 4702

Email: l.byrne@cqu.edu.au

Concerns / Complaints

Please contact Central Queensland University's Office of Research (Tel: 07 4923 2603; E-mail: ethics@cqu.edu.au; Mailing address: Building 32, Central Queensland University, Rockhampton QLD 4702).

Appendix 4: Informed consent form

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

INFORMED CONSENT FORM

I consent to participation in this research project and agree that:

1. An Information Sheet has been provided to me that I have read and understood;
2. I have had any questions I had about the project answered to my satisfaction by the Information Sheet and any further verbal explanation provided;
3. I understand that my participation or non-participation in the research project will not affect my employment;
4. I understand that I have the right to withdraw from the project at any time without penalty;
5. I understand that focus group and interviews whether via phone, video conference or face-to-face will be recorded and transcribed;
6. I understand that the interviews will be kept in secure storage and only available to the research team;
7. I understand that all transcriptions will be coded and my identity will only be known to the research team;
8. I understand the research findings will be included in the researcher's publication(s) on the project and this may include conferences and articles written for journals and other methods of dissemination stated in the Information Sheet;
9. I understand that to preserve anonymity and maintain confidentiality of participants that fictitious names may be used in any publication(s);
10. I am aware a Plain English statement of results will be available to me if I request it;
11. I agree that I am providing informed consent to participate in this project.

Signature: _____ Date: _____

Name (please print): _____

I wish to have a Plain English statement of results sent to me (please tick):

YES ☐ (please provide preferred contact details below): **NO ☐**

Postal Address: _____

E-mail Address: _____

Appendix 5: Demographic

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

DEMOGRAPHIC QUESTIONNAIRE

Selection Process
In order for the research to be as informative as possible, participants must be currently employed in senior manager roles within the mental health sector and have a range of experiences in the employment or non-employment of lived experience workers.

The information below will not be used in any reporting or publication in a way that could inadvertently identify participants, the selection criteria is used only to ensure a diversity of perspectives. All participation will be strictly confidential.

For more information email Louise, or fill in the following and return to Dr Louise Byrne at l.byrne@cqu.edu.au

Name_____

Q1. Please provide your job title and describe your role as briefly as possible

Q2. Does your organisation employ lived experience workers?

Q3. Are you or have you ever been responsible for the supervision of lived experience workers?

Q4. If yes, how many and what role/s do they hold within the organisation

We will have a limited number of spaces available in focus group but one-on-one interviews will also be offered. We also realise some people would prefer not to participate in focus groups. Please indicate below whether you are happy to be contacted for either focus group or interview.

Please contact me for:

1. Either focus group or interview

2. Interview only