

Recovery as a Lived Experience Discipline: A Grounded Theory Study

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Lived Experience workers and Recovery oriented practice- what is the link?

Take Home Messages

- Recovery is government mandated and a core facet of mental health reform.
- Recovery implementation has been inhibited by a lack of education and understanding from clinicians.
- There are significant barriers to the implementation of Recovery-focused practice -these are recovery is co-opted, lack of Recovery uptake, and Recovery denial by mental health professionals.
- For a genuine Recovery focused mental health system to be developed, Lived Experience workers must be enabled to take their role as Recovery experts and leaders.

Aim

To explore the potential of lived experience workers in contributing to the implementations of Recovery based service delivery within the Australian mental health sector

Background

The concept of Recovery was created by people with mental health challenges to describe their own experiences and journeys and an identity beyond the limits of diagnoses. Individuals with a lived experience of mental health challenges championed the concept of Recovery in opposition to the dominant belief that these challenges were unremitting

The term “lived experience” refers to the unique perspective provided by people who have experienced significant mental health challenges, service use, and Recovery. Lived Experience workers work from the perspective of their unique lived understanding.

The lived experience definition of Recovery is described as a life that is chosen, beyond the constraints of illness or illness identity; a life of hope that is unique and deeply meaningful to the individual.

Recovery is frequently co-opted, with clinicians continuing to hold ideas of symptom reduction and clinical recovery, hindering reform and Recovery-informed policies and processes.

Method

Interviews were conducted with 13 people employed to work from a lived experience perspective.

Results

Three factors that were found to inhibit lived experience roles- Recovery being co-opted; Lack of Recovery uptake; and Recovery denial by mental health professionals.

Recovery is Co-Opted

The concept of personal recovery was created by people with lived experience. Lived experience concepts of Recovery are distinct from clinical interpretations. Yet the concept of Recovery changed from its original meaning so that it was no longer a useful term and the concept of Recovery was so co-opted that Lived Experience workers felt compromised in their role. The difference between clinical and lived perceptions of Recovery centred on power and control.

"I think the word "Recovery" has been co-opted so greatly, that's why I don't use it. I believe the way it was used originally was really powerful."

- Brydie

"Look at me as a person and me the driver of my recovery. Sadly, the clinical work I was doing, we were the drivers and it wasn't about them [people accessing the service]."

- Geoff

Recovery and lived experience work are directly linked to and informing each other.

"The whole basis of employing consumer workers is they provide a special significant different perspective on Recovery, on supporting people who have mental health issues... We [lived experience workers] see Recovery as a human growth process. You could call having a mental illness just like a midlife crisis ... it's a hurdle or a hiccup, which can and has to be overcome."

- Roger

I do a lot of teaching around recovery and I use it as a tool because I do think for me the essence of recovery is about us reclaiming control of our lives and that's what peer [lived experience] work is about, too. It's about us reclaiming space for our experiences collectively to be understood as having value and that we can do things and there's value in what we do, immense value, and that only we can do it, and for me recovery is exactly the same."

- Byrdie

Recovery Uptake

The uptake of Recovery within mental health services was impacted by:

Clinical misunderstanding of recovery concepts

A lack of training of mental health professionals

Insufficient time for mental health professionals

"Recovery is what they [non-government/community sector] talk about. They struggle, I think, because their job has been paternalistic. That is really hard to shift from and it's really easy to pretend you're doing Recovery when actually you're just doing rehabilitation."

- Byrdie

"The people there [clinicians] are so stressed for time they don't have time to look at what Recovery is and look at strength-based practices and person-centered approaches."

- Margaret

Nongovernment services have made some progress implementing Recovery. However, a lack of lived experience workers impacted poor Recovery uptake in government services.

"The non-governmental organisations' successes in implementing Recovery was seen, at least in part, to be due to an understanding that to do Recovery stuff they have to have consumer [lived experience] leaders involved and they have to have consumers participating in every level and, I think, some organisations are doing that really, really well."

- Byrdie

"There isn't much opportunity for lived experience workers within clinical settings [government services] at the moment. So people don't have access to the lived experience, or consumers don't, and workers tend to be scared of it."

- Margaret

A key barrier for Lived Experience workers in government services due is environments being incompatible with lived experience work and Recovery.

"I think the biggest issue for me was having a peer worker with lived experience work in an organisation that doesn't deliver a peer support [Recovery informed] work model. I see that as a recipe for disaster because that's a clash, two completely different frameworks of work."

- Geoff

Recovery Denial

Denial of Recovery was most commonly believed to be due to working within an acute care environment and clinicians who predominantly saw people when they were acutely unwell and did not witness other stages of their recovery and wellness.

"In the acute setting it's very hard to get them [clinicians] to accept Recovery as relevant to their clinical practice because—we call it the clinician's delusion. They always see, in an acute setting, people who are unwell, so they don't believe or they never see people going home, getting on with their lives, recovering, getting better and being productive, contributing members of society. So they think people are always unwell—a bit of denial."

- Roger

"Mainstream mental health [government] services have this view, they only see people that are in crisis and that are really, really bad and I don't think they have much of a concept of Recovery and what people can achieve in Recovery."

- Alex

Some clinicians may view Recovery as a process limited to those with less significant mental health challenges.

"Either not believing in Recovery or seeing that some people recover because their experiences weren't that serious in the first place ... So it's like some people recover and they were normal anyway, that there's this idea that some people are basically normal and something kind of happens and there's probably an explanation for it."

- Brydie

When a denial of the concepts of Recovery was believed to exist, limitations for the lived experience role occurred—due to clinicians reportedly not seeing lived experience practitioners as having ever been “real” mental health consumers.

A lot of consumers are told they won't recover. So I suppose, then, that translates to, if you're a consumer [lived experience] worker, they expect you to not be able to do much. Not being very capable of very much at all."

- Margaret

Discussion

- Mental health professionals were seen as often misunderstanding and misusing the term Recovery confusing personal recovery with “clinical recovery”.
- Mental health professionals were also seen as often not believing Recovery was possible.
- Lived Experience workers were often marginalised or employed in tokenistic roles.
- For reform to be successful, there is a need for mental health professionals to view Recovery as a central tenet of their work
- Until and unless all mental health workers accept Recovery, reform will be severely inhibited.
- Lived experience work and Recovery are linked and Lived Experience leadership is essential to successful Recovery implementation and guiding Recovery education, as well as employing larger numbers of lived experience roles within the sector.

Conclusion

Lived Experience practitioners must be recognised as leaders in Recovery if these barriers are to be overcome and genuine Recovery-focused practice is to become a reality