

# The Stigma of Identifying as Having Lived Experience Runs Before Me: Challenges for Lived Experience Roles

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**What are the common work experiences encountered by the Lived Experience workforce? What impact does stigma and discrimination have and how can we address these issues?**

## Take Home Messages

- Lived Experience workers improve outcomes for people receiving services
- Lived Experience workers can contribute to reducing stigma
- Lived Experience workers often face stigma and discrimination. This can be so frequent to be accepted as a 'normal' part of working life
- Lived Experience workers also face professional isolation
- For Lived Experience roles to be as effective as they could be then stigma and discrimination need to be addressed

- Greater education and championing by Allies is needed to create safe working spaces for Lived Experience workers

## Aim

This research aimed to better understand the impact of stigma and discrimination experienced by Lived Experience workers in a variety of roles and settings across Australia.

Lived experience workers are employed to use their 'lived' understanding of mental health challenges within their work.

Lived Experience workers are employed in a range of mental health settings to:

## Background

Across a wide variety of roles and organisations Lived Experience workers also provide:

Assist people accessing services to navigate the system

Promote recovery for those accessing services

Challenge discriminatory attitudes

Promote better understanding of recovery for organisations and those in clinical roles

Direct support

Education and training

Advocacy

Contribution to system design

Lived Experience workers have a range of titles, but the core qualification across all of the roles is having had a personal lived experience of recovery and a unique understanding of what other people accessing mental health services experience.

This 'unique' understanding includes an understanding of experiences such as:

Marginalisation

Oppression

Loss of social status

Self-stigma

Stigma

Lived Experience roles which primarily focus on support for people accessing services provide:

Empathy

Hope

Connection

Genuine understanding

When employed to educate or work in systemic positions (e.g. policy, research etc.) the Lived Experience worker is able to be a bridge of understanding to help others better understand the needs of people accessing services and what service providers can do to provide better support.

Research shows that effective lived experience roles can:

- Supplement or aid traditional mental health services
- Improve outcomes for people with mental health challenges
- Reduce overall health care expenditure

Unfortunately, despite the unique features and potential benefits of these roles, the effectiveness of Lived Experience work is negatively impacted by high levels of stigma and discrimination.

## Method

13 participants from a broad range of roles and Australian states were asked to describe their experience of working in a Lived Experience role.

Interview data was examined in terms of frequently identified experiences.

## Results

Stigma and discrimination was identified by Lived Experience workers as a common experience that negatively impacted the effectiveness of their role.

Three core ideas were found to contribute to the negative attitudes towards Lived Experience workers: 'stigma is normal', 'Lived Experience workers are treated differently' and 'professional isolation'.

## Stigma is Normal

People participating in the research reported that:

- Stigma/discrimination was a common experience
- Most Lived Experience Workers came to accept it as a 'normal' part of

their work life

- Lived Experience Workers said they needed to be careful of not reinforcing low expectations and stereotypical attitudes from their colleagues and as a result felt pressure to always go above and beyond to be accepted/credible
- Some Lived Experience Workers felt judged and therefore tried to overcompensate and hid any vulnerability to not be seen as 'unwell'

### Quote 1

“...what I say about stigma generally is it’s a bit of an optional thing if you receive stigma from mental illness. If you’ve got enough clues about life you won’t say “I have a mental illness” or “I have this or that disorder”

### Quote 2

“I do think I’ve had to overcompensate. I’m aware of how I dress, of how I move, of how I engage, that there is always the potential that I will be misread as being inappropriate, and that being due to my lived experience rather than just a personality thing. “

### Quote 3

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# Experienced Discrimination

Participants experiences included:

Colleagues asking intrusive and inappropriate questions about their lived experience

Some mental health professionals/clinicians treating Lived Experience workers as if they were people accessing services rather than workers

Colleagues showed surprise when high quality work was done by Lived Experience workers, indicating lower expectations and perceived value of Lived Experience workers

## Quote 1

“...reactions from some staff makes me feel that the stigma of identifying as having a lived experience runs before me, before any sort of professional credibility. I was a high level performer in community development in the non-government sector before I took this job and I come in here and it’s as if the only thing people see is the tag of “consumer” and you have to work really hard to get recognised.”

## Quote 2

“Somebody asked me a question about what my diagnosis was at one stage and I thought “God nobody’s asked me that for freakin’ years and I’ve had seven, which one would you like?” I don’t answer that question anyway. I just

said “sorry, I don’t answer those questions”.

### Quote 3

“Certainly they might think they know all about consumers because they treat them [consumers] all the time, but I’m not unwell. I’m not somebody they need to medicate or organise services for. So their role with me is quite different even though I identify as someone that has mental health problems.”

## Professional Isolation

Participants described:

- Colleagues not interacting with them, not asking their opinion or advice even about recovery concepts or practices
- Professional isolation making Lived Experience workers feel unmotivated and unimportant. These feelings had at times lead to quitting the role
- Being marginalised and isolated, particularly those Lived Experience workers within government-run organisations
- Government services still being seen as stuck in ‘medical model’ thinking, which was seen to include stigmatising/unhelpful beliefs about people accessing services and Lived Experience workers
- Moving from government to non-government or Lived Experience-run services was viewed as more positive, with reports of better treatment and inclusion and feelings of being accepted and valued

### Quote 1

“A psychiatrist was talking about how consumers and carers belong under the table. I went, “I’m a consumer consultant,” and they literally jumped backwards, stepped away from me in fear. There was a lot of stigma in that particular organisation. I was left to my own devices, no-one noticed if I rocked up or not and given tokenistic and menial jobs to do.”

### Quote 2

“Some people can get very protective of their professional boundaries... I keep pretty much to myself unless I’m asked to help someone. But it doesn’t happen very often... what I’m saying, the mental health workers don’t talk to me.”

### Quote 3

“No one has ever asked; no other mental health professional; one of the nurses, social workers, occupational therapists or psychologists have asked me about recovery. Ever. I think that’s damning, ‘cause I don’t know if you’re getting the sense, I know a little bit about recovery.”

### Quote 4

“In NGOs [non-government organisations] it’s really amazing to see how much I’m welcomed as part of the team and that my experience is actually seen as something worthwhile that I can contribute rather than in clinical [government] where it seems to be the opposite.”

# Discussion

Prejudicial attitudes and discrimination were common and impacted the effectiveness of Lived Experience work.

Many Lived Experience workers were so used to stigma they saw it as a normal part of their work.

Professional isolation and feeling outnumbered was also common and suggested that more Lived Experience roles are needed to counter the isolation and challenge stigmatising/negative attitudes.

Research revealed that some mental health professionals are skeptical about the value of Lived Experience roles and some colleagues were fearful or simply choose not to interact.

Lived Experience workers reported that the attitudes of others and isolation were a barrier to them working effectively.

There are a number of actions that can be taken to reduce stigma and discrimination:

Foster greater understanding of Lived Experience roles, particularly in government services

Increase employment of Lived Experience workers to reduce professional isolation

Share research on the value of Lived Experience roles to increase understanding and improve attitudes

Greater accountability measures for organisations to ensure workplaces are safe spaces for Lived Experience roles

## Conclusion

Lived Experience workers have the ability to play an important role in reducing stigma and discrimination but they need to be supported rather than face stigma themselves in the workplace.

[Click here to see the paper](#)