The Global Need for Lived Experience Leadership

Are there enough meaningful opportunities for Lived Experience Leadership? Why does this matter?

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Aim

To examine global research, literature and expert opinion to identify common challenges and experiences of the Lived Experience workforce internationally, as well as future needs.

Background

The recovery approach requires the role of people with a lived experience of recovery. This needs to include people in recovery at three levels:

1. People with a mental health diagnosis feeling empowered to seek a life of meaning and purpose

2. Employment of people in recovery (Lived Experience roles) to inspire hope, provide empathy, engage in advocacy, and help current service users navigate the mental health system

3. Realisation of disability rights which state "nothing about us without us," meaning that people with a lived experience of recovery should be in senior leadership roles so that they can impact policy, planning and program development

While the first two levels described above are making progress, the third is still very much lacking.

Research shows that there are a number of barriers for the Lived Experience workforce, which makes it difficult for them to attain management positions:

- Low remuneration and funding
- Lack of role clarity
- Lack of career path
- Lack of training opportunities, supervision and/or support
- Risk of co-option

Method

Peer-reviewed research and research published by organisations around the world was examined and analysed to give an indication of the progress of the Lived Experience workforce globally towards the three levels described.

Findings

In the Southern Hemisphere

Currently, in the Southern Hemisphere the only countries which have recovery as a clear direction in national policy are Australia and New Zealand. There are increasing but still ad hoc examples of Lived Experience leadership roles in Australia and New Zealand. Other countries such as Asia and South America still push mental health as a biological illness with an almost exclusive emphasis on use of medication to manage 'symptoms'.

Peer work is limited in areas of Asia. Examples of progress from specific countries include:

- Cities in Asia such as Hong Kong and Singapore have developed peer workforces but still with tight controls from non-Lived Experience management
- Japan and China was still in the infancy stages of having any Lived Experience workforce
- In Indonesia there were only 20 trained Lived Experience workers at the time of publication

Lived Experience workers could play a role in supporting a more recovery focused mental health system. But to get more Lived Experience workers, these countries need Lived Experience leaders who can support and train a Lived Experience workforce.

Lived Experience Leadership & Recovery

Lived Experience leaders have an advantage in understanding areas where traditional knowledge has not been effective. One key area is the concept of recovery. Mental health professions tend to misinterpret recovery concepts and try and make the concept fit within a medical understanding.

People with lived experience bring a personal understanding of recovery and could help with making mental health systems more recovery oriented – but they need to have the opportunity to meaningfully contribute and for their contribution to have potential for impact/change.

Collaboration, Coproduction, & Championing

The role of 'allies' is significant in supporting the success of Lived Experience leadership. Allies are people in traditional or clinical (non Lived Experience roles) who pro-actively support and provide opportunities for Lived Experience leadership. This includes allies being willing to share or even give up power. To be effective, allies will:

- Champion Lived Experience roles and concepts
- Collaborate with Lived Experience Leaders
- Respect Lived Experience knowledge and expertise
- Co-produce and co-design with Lived Experience leaders/workers

If power is not shared and Lived Experience workers do not have an equal say there is a risk that the roles become tokenistic.
Lived Experience leaders employed in senior roles are required to help the Lived Experience workforce continue to develop and create impact.

The authority of Lived Experience workers and leaders in understanding recovery concepts and practice is central and must be accepted.

To Make Change We Need Lived Experience Leadership

There is a need for people with lived experience to be in decision making roles within the mental health sector to improve service delivery and to ensure better outcomes for people accessing services. By developing and including Lived Experience workers, the human rights of people accessing services are placed at the heart of practice and recovery concepts and practices can gain traction. Having Lived Experience leadership roles helps change policy, such as reducing restrictive practices, and also helps others to better understand what 'lived experience' is and why it is important.

In summary, research also shows that Lived Experience roles:

- Reduce restrictive Practice
- Reduce service costs and spending
- Improve outcomes for people accessing services

Conclusion

For real change to occur in the mental health system, Lived Experience workers must be employed in decision making roles, including executive level roles. This requires more attention and resources for Lived Experience training and skill development. If we don't take action now then those opportunities may be missed.

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