

A Role for Lived Experience Mental Health Leadership in the Age of COVID-19

Byrne, L., & Wykes, T. (2020). A role for lived experience mental health leadership in the age of Covid-19. Journal of Mental Health, 29(3), 243-246. doi:10.1080/09638237.2020.1766002

Could changing views of mental health as a result of COVID-19 provide opportunities for Lived Experience in research?

Take Home Messages

- COVID 19 highlights the need to stop pathologizing emotional experiences and recognises our shared emotional impact and shared humanity.
- COVID 19 also brings a golden opportunity for increased Lived Experience research.
- Lived Experience research and co-production holds potential for more relevant research that is better able to bring changes to improve experiences of people experiencing distress.
- People with Lived Experience have answers through collective knowledge and expertise in surviving and thriving with mental health challenges and in managing trauma induced situations.

COVID-19 has increased uncertainty and had significant additional negative impacts on the mental health internationally.

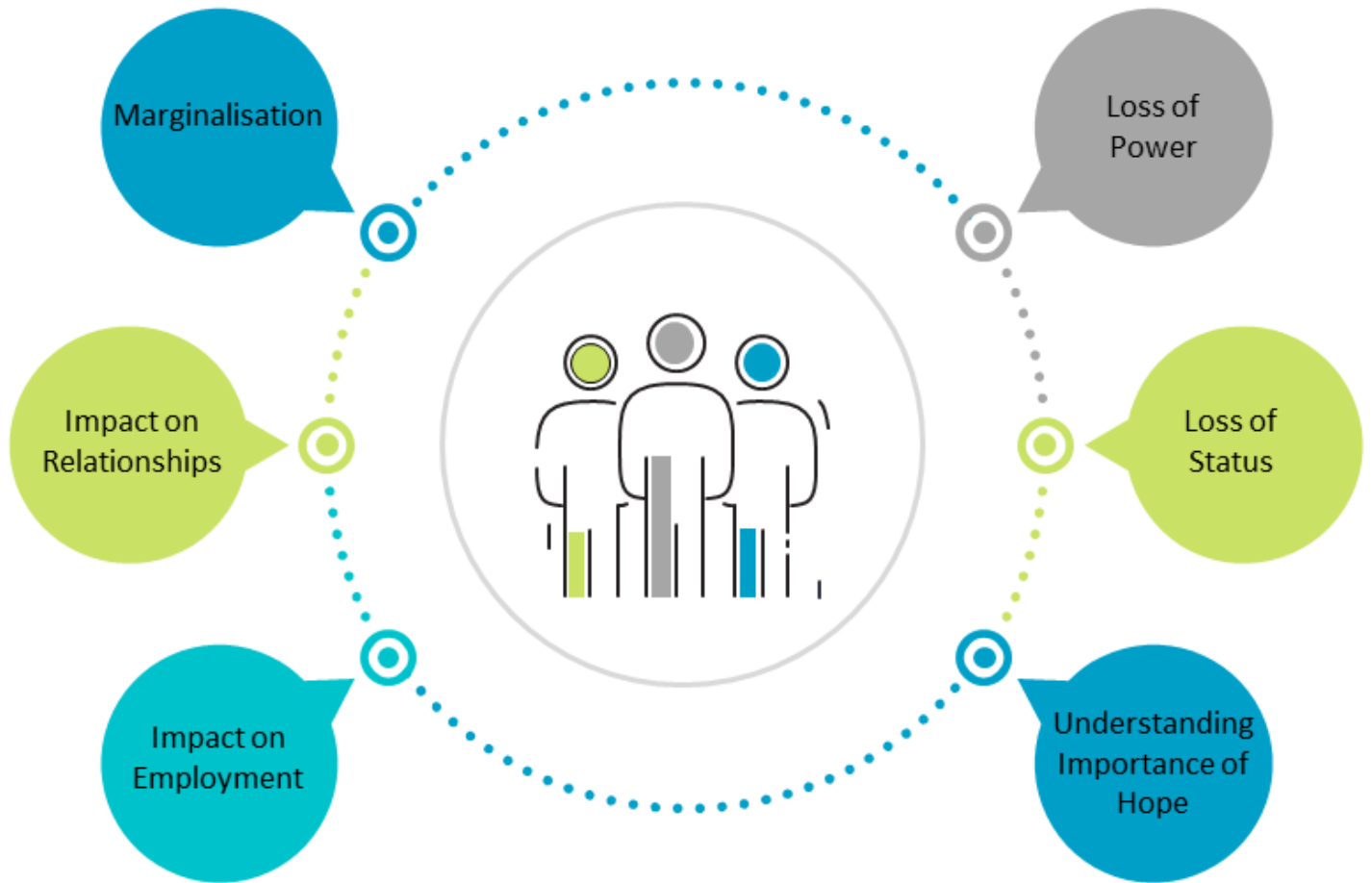
The current state of the world presents an opportunity to connect via this common experience of trauma and by sharing strategies and stories to move forward. The Lived Experience community can play a key role in this.

As the Lived Experience workforce has grown, so has recognition of the potential for Lived Experience roles. However, the bio-medical perspective still largely resists the involvement of people with lived experience, largely due to myths and misconceptions.

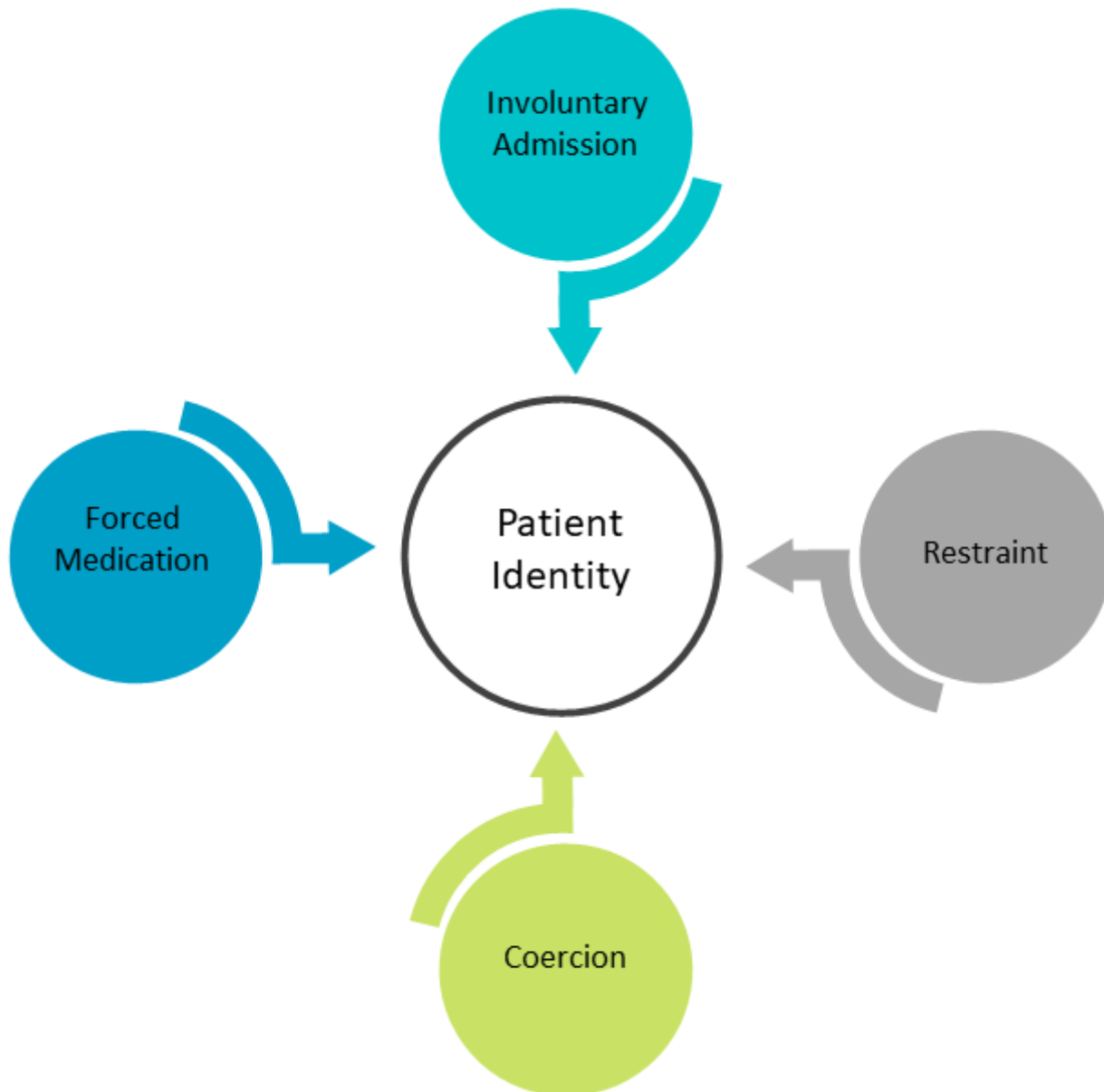
While everyone has some experience of adverse events, lived experience refers to mental health challenges that significantly impact a person's life to a degree that they redefine themselves, their future and their place in the world.

Lived Experience workers use their experiences to help others. The Lived Experience workforce is values based and involves a commitment to social justice and being an 'agent of change'.

Lived Experience perspective is not about specific diagnoses but more about universal experiences such as:



For people accessing services, particularly those who have experienced involuntary admission, forced medication, coercion and restraint, it can be hard to feel safe to express their views on the mental health system and services. Some people develop a 'patient identity' as a result of service experiences and become passive and obedient in ways that deny their autonomy and full citizenship.



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The unequal power between traditional mental health workers and people with a lived experience highlights the importance of Lived Experience work – an ability and willingness to disagree with dominant bio-medical views.

With regards to mental health research, Lived Experience workers can provide a bridge between mainstream research and service users, making research

more relevant to the people most affected.

Co-design with Lived Experience workers can result in initiatives and research that can:

Be written in plain English

Framed in a more relevant way

Be less specific

Be more accessible

Be recovery focussed

Lived Experience roles give a common-sense, first hand understanding and approach to thriving with mental health challenges.

Due to COVID-19 there has been increased funding for mental health research.

With such an important perspective, it is crucial this increased funding provide opportunity for Lived Experience research to be given greater priority.

For this opportunity to be realised there needs to be a whole of sector refocus, increased willingness from funding bodies, academic institutions, journals and individuals to embrace Lived Experience led research, and challenge their existing world view to work collaboratively with Lived Experience

perspectives.

[Click here to see the paper](#)