People with experience of mental health conditions should be paid to help others, says researcher

March 5 2024, by Bernadette McSherry

Credit: Tima Miroshnichenko from Pexels

For anyone diagnosed with physical illnesses, like cancer, it's common for services and organizations to provide peer-support programs.

Programs like these acknowledge the need for people to learn how to navigate all of the services and information from those who've already experienced the illness themselves. They can also provide important therapeutic connections.

Until relatively recently, the knowledge and perspective of people living with mental health conditions have been largely ignored or dismissed.

The growth of the "lived experience" workforce over the past two decades alongside the rise of the mental health consumer movement give us an opportunity to redress this.

What is 'lived experience?"

While the term "lived experience" is not without criticism, it is usually used in mental health to recognize the direct experience of people with lived/living experience of mental ill-health and/or recovery—this is sometimes called the consumer perspective.

Three years ago, the six-volume Final Report of the Royal Commission into Victoria's Mental Health System was tabled in a special sitting of the Victorian Parliament.

The third volume, Promoting Inclusion and Addressing Inequities, includes a vision for the future mental health and well-being system which "will see people with lived experience of mental illness or psychological distress in multiple and substantive leadership positions, working collaboratively with others to lead and influence change and balance power."

Recommendation 29 calls for a new non-government agency led by people with lived experience to deliver accredited training and resources; develop and deliver mental health and well-being services; and facilitate

collaboration across lived experience networks and organizations.

The Royal Commission made 74 recommendations in all, many of which are now being implemented, but Recommendation 29 is yet to be funded, despite the Commission emphasizing that "the experiences, preferences and expertise of people with lived experience of mental illness or psychological distress must be integral to the implementation of all recommendations."

Reforming the mental health system is complex and the Royal Commission set out a decade-long timetable for the implementation of all of its recommendations.

There are now calls for the Victorian government to prioritize funding for the new agency to ensure the momentum for this transformational change continues.

Why is lived experience important?

The movement to have people with lived experience share information and support others to make decisions about their own mental health has provided the impetus for employing people with lived experience in services, academia and advocacy organizations.

This engagement is important.

In the words of British sociologist and social theorist Nikolas Rose, "the alternative knowledge that service users have developed of the social and interpersonal foundations of mental distress … might genuinely meet the needs of those experiencing profound crises in their lives."

One British study found that when people with mental health conditions were engaged as active participants in mental health services, there were

improvements in therapeutic relationships and fostering supportive cultures.

Peer support roles were also associated with significant reductions in hospital stays.

At the same time, mental health practitioners have emphasized the importance of collaboration with people with lived experience because of the need "to reframe experiences of mental illness, distress and alienation by turning them into human, rather than technical, challenges."

Challenging dominant ideas

In the mental health sector, the involvement of lived-experience workers in planning, delivery and evaluation of services has increased, but there are challenges to full and active participation in reshaping collaboration.

Mental health researchers have pointed out that these "involvement efforts are too often accompanied by empty promises, insufficient funding or commitment, and superficial gestures (e.g., membership on advisory boards), with no real power to set agendas, influence decision making, or bring about structural change."

This is partly because collaboration with people who have lived experience challenges the dominant ideas of knowledge while providing opportunities to explore new ways of improving their mental health and well-being.

There's also "an epistemological hierarchy of knowledge producers" in the mental health sector with "university-trained researchers sitting at the apex."

In addition, lived experience workers may not be perceived to be 'professionals' in the same way as psychiatrists, psychologists and mental health nurses.

In fact, there is the view that "[c]onsumer-work is an atypical occupation: unlike the worker who may be employed for their IT skills but also has a mental illness, consumer-workers are employed because they have a diagnosis."

Some may view lived-experience workers as only able to offer personal perspectives, rather than representing a "discipline," which is generally considered a branch of knowledge studied in higher education.

Lived experience as a discipline

This view that lived-experience workers are not professionals is now being challenged.

In fact, some universities in the United Kingdom and Canada are offering the subject "Mad Studies" as part of an emerging academic discipline.

There is also a focus on lived-experience work as a discipline in its own right.

A study by Australian researchers sets out a conceptual model of diverse consumer views that aim to underpin collaboration across the mental health system. The message is that "engaging with only a single consumer or survivor as 'representative' is tokenistic and futile."

In order to see real change, we need to build the lived-experience workforce to a critical mass.

Sharing wisdom

There are several organizations that provide advocacy and support for people with mental health conditions.

For example, the Royal Commission pointed to the role of the Victorian Mental Illness Awareness Council as essential to "progressing the Commission's reform agenda."

There are also peer-run programs and initiatives like Safe Haven and the Big Feels Club that provide a way of communicating with others with lived experience.

But there remains a gap. We need an independent agency led by people with lived experience which can turbocharge system-wide reform in order to help those who most need the wisdom they can share.

Provided by University of Melbourne

Citation: People with experience of mental health conditions should be paid to help others, says researcher (2024, March 5) retrieved 27 April 2024 from https://medicalxpress.com/news/2024-03-people-mental-health-conditions-paid.html