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A role for lived experience mental health leadership in the age of Covid-19

In 2020 an invisible assassin has swept across the world, creating chaos, confusion and uncertainty. Covid 19 has taken many people's health, some people's lives and the lives of loved ones. It has destroyed livelihoods and put the financial futures of billions at risk. We are helpless, there is nothing to fight back with. We are trapped, we have to stay in our homes. We are physically isolated, our usual freedoms and way of life suspended. As a result, our ability to enact fight or flight is inhibited, increasing the likelihood of lasting impacts on mental wellbeing (van der Kolk, 2014). Life as we know it, at least for a time, has changed so significantly we are reimagining our futures in a variety of ways, with no idea what's really in store for us. We are collectively holding our breath, fearing the worst and hoping for the best. Never has there been a greater opportunity to stop pathologising the emotional experiences of human beings and start connecting over commonality, sharing stories and strategies to collectively work our way forward. As a global community, we are all engaging with personal recovery on some level and trying to create a new life, with meaning and hope, beyond the effects of Covid 19. At a time when there is a global mental health crisis, the lived experience community has answers that are highly appropriate to the trauma-induced situation we're all facing.

As the prevalence of lived experience/service user/peer/survivor/Mad perspectives have grown in recent years, so recognition of the potential benefits of lived experience roles is growing. There are examples of lived experience work being embraced by organisations and enabled to contribute to systems transformation (Jackson & Fong, 2017). However, instead of welcoming the hands-on, been-there-done-that perspective lived experience brings, the established medical paradigm largely continues to resist the involvement of lived experience, with considerable push back and unwillingness to engage still occurring (Happell et al., 2015; Jones et al., 2020). There are a number of misconceptions or beliefs underpinning this unwillingness.

"But don't we *all* have lived experience?" is one common way to question the value, uniqueness and need for designated lived experience roles. The answer to this question is usually yes, and no. Yes we all have adverse experiences, times when we're down, stressed, anxious, paranoid etc. But in the lived experience movement we define 'lived experience' as mental health challenges that have caused life as we knew it to change so significantly we have to reimagine and redefine ourselves, our place in the world and our future plans. As of 2020, thanks to Covid 19, we do all have something a lot closer to this 'lived experience'. But we don't all have the expertise, the collective knowledge of the lived experience movement.

Decades of dedicated thought, debate, study and work has generated an alternate, empowering way of viewing ourselves and our experiences outside the bio-medical lens. This is the result of thousands of people with lived experience unpicking what is unhelpful in existing concepts of mental health and the ways we learn to view ourselves within the system. The collective itself is important, for as Rose espouses, the level of the group is stronger than the individual and allows for more effective advocacy (Rose, 2014). Key to co-production or leadership by lived experience is this common knowledge base, not simply lone voices, but experiences contextualised within the broader thinking. The lived experience perspective is not about individual illness or specific diagnoses, but rather universal experiences, such as marginalisation, loss of power, status/citizenship, employment, a stable home and relationships. It's not just about loss but also about regaining hope and understanding hope is essential in the context of recovery or healing (Deegan, 1996, September 16). Importantly, it's about learning how to use those experiences in a way that's useful to other people.

Lived experience is a discipline and on the way to becoming a recognised profession (Roennfeldt & Byrne, *In Press*). It has its own underlying philosophy and values distinct from other disciplines. Lived experience work is emancipatory, values based, informed by and springing from a commitment to social justice (Gillard et al., 2017), emphasising the lived experience role of the change agent (Gillard et al., 2015).

This then raises another common misconception, that "anyone with a lived experience will do" and highlights the importance of distinguishing between people who happen to have a lived experience and those who intentionally learn to view from a lived experience perspective, and why that matters. For some of us the service journey includes involuntary admission, forced medication, coercion and restraint (Daya et al., 2020). For many, there have been lessons about compliance and being a 'good patient'. As a result, we can develop what's commonly referred to as the 'patient identity' (Mead & MacNeil, 2006), typically passive and obedient and often not the same as an adult with autonomy and full citizenship. Lessons of passivity and agreement can sink in deeply and even become unconscious, particularly when we are grateful for any help at all in a situation that feels desperate. Consequently, many people with lived experience lack the confidence or ability to articulate their views, particularly if they contradict the status quo and especially when speaking to people who hold similar roles to those who have taken choices away from us. Gaining full sovereignty of our lives often requires some discarding of the inappropriately obedient ways we are encouraged to behave

within services (Mead et al., 2013). But on leaving services, there is no identified process of regaining and reclaiming that autonomy. Issues of power and feeling entitled to participate fully are at the heart of co-production. The fundamentally unequal power differentials between traditional mental health workers/researchers and people with lived experience underline the importance of the change agent function of lived experience work, i.e.: an ability and willingness to disagree with dominant views.

An adjacent issue is risk to the authenticity of lived experience work when organisations forgo designated roles/perspectives, substituting instead people working in traditional mental health roles who happen to have lived experience (psychiatrists, psychologists, social workers, mental health nurses etc.). Trying to serve multiple disciplines or perspectives just muddies the waters. This is not to say there is no room for the lived experience of people in traditional mental health roles, but that one cannot replace the other and that designated roles, committed perspectives, are needed to do justice to lived experience thinking.

With lived experience guidance, initiatives and research are framed differently, in language and concepts that are more ‘plain English’, less service-specific, and consequently acceptable and accessible to a broader range of service users. Equally compelling, is the deep, internal and applied understanding of recovery that lived experience workers hold. No matter where you are in the mental health sector or what your focus is, recovery is the underpinning philosophy we are all expected to work from. However, recovery is still a fuzzy concept for most who have not experienced it. As a result, in 2020 mental health researchers are still asking “What Is ‘Recovery’?” and as the New York Times article demonstrates, it’s those with lived experience who have the answers (Carey, 2020, February 25). Perhaps more importantly, we have the questions. As the article explains, commonly researchers from traditional backgrounds don’t understand the mental health experience well enough to know how to approach participants or design questions that are relevant and likely to receive meaningful responses. This is the crux of the issue, why meaningful co-production and lived experience leadership are essential in any research. Lived experience provides a bridge, a means of translation between mainstream research and service users. This in turn creates opportunity for research to be more relevant to the people most affected.

Due to SARS-Cov-2, governments are pledging billions in additional funding for mental health research (Australian Government, 2020, March 29; BBC News, 2020, April 14). Will the funding for this new research be funnelled into the same channels with an emphasis on second hand or outsider knowledge? Or will this be the golden opportunity for lived experience knowledge be given greater priority? There are sparks of hope, existing patient and public involvement policies in the UK highlight the need for lived experience involvement in research (NHS England, 2017; The National Institute for Health and Care Excellence, 2013). However, involvement of lived experience perspectives is still often not engaged during conceptual design stages, limiting

influence and impact. Additionally, power differences are often not addressed (Ocloo & Matthews, 2016). In terms of lived experience leadership within research, there are additional barriers. Not the least of which being a lack of journals who understand, value or publish lived experience produced or focused work.

In this journal, there is an articulated commitment to lived experience priorities and views, with a call for people in identified roles to make clear their lived experience on submission. The *Journal of Mental Health* has emphasised the inclusion of lived experience authors (Byrne et al., 2019; Pinfold et al., 2019; Robertson et al., 2019; Robotham et al., 2016; Webber et al., 2014) and been successful on our editorial board, in our editorials (Carr, *In Press*; Sweeney & Taggart, 2018; Wykes et al., 2019) and in the types of research we accept (Farr et al., 2019; Happell, Bennetts, et al. 2019; Happell, Gordon, et al. 2019; McCabe et al., 2018; Mulfingher et al., 2019; Twamley et al., 2020). We want to continue to encourage these papers and particularly those led by lived experience perspectives. This is difficult to measure as some people do not choose to clarify their personal experience. More research teams making transparent the involvement and leadership of lived experience perspectives would be useful. Our plan is to discuss these issues with our publisher to see if we can collect data that will enable us to see if we are meeting our goal of a level playing field for all.

The value of multiple, diverse perspectives in supporting people accessing services is acknowledged in a recent *Lancet Psychiatry* position paper. The paper was co-authored by lived experience researcher and *Journal of Mental Health* editor Angela Sweeney, and like this journal, was multi-disciplinary (Holmes et al., 2020). Lived experience roles provide a common-sense, firsthand understanding and approach to surviving and thriving with mental health challenges. It is therefore difficult to imagine a reasonable argument for not including lived experience roles as one of the multiple perspectives guiding research. Thanks to Covid 19, the future of conceptualising and researching mental health includes the possibility for greater inclusivity and broader relevance. Realising this potential will require a whole sector re-focus, including the willingness of funding bodies, academic institutions, journals and individuals to create space, challenge their existing worldview and collaborate meaningfully with authentic lived experience perspectives. Like the *Journal of Mental Health*, will you be part of the change?

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