A Lived Experience Program

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Lived experience is the knowledge and understanding generated from living through a situation or event. In the context of mental health, sharing personal narratives of how people have overcome mental distress, injury and illness has multiple benefits including tackling stigma about mental illness. "Lived Experience workers have unique knowledge, abilities, and attributes. They draw on their own life-changing experience, service use and their journey of recovery and healing, to support others" (National Mental Health Commission 2021)

In recent years lived experience has emerged as best practice thinking both nationally (Byrne et al 2021) and internationally (Patel et al 2018). An increasing number of organisations have, or are planning to, procure employees or volunteers with a lived experience of mental health recovery to provide "hands on support, education and training, systemic advocacy and contributing to system design" (Byrne et al 2019, p. 260). This discussion paper recognises the value of lived experience in a range of roles and tasks but focuses on its deployment in networks of speakers who harness the power of storytelling to communicate personal wellbeing struggles and how they were overcome or otherwise managed.

Background

Mental ill health is a significant problem in the police and emergency services nationwide. Beyond Blue (2018) Answering the Call research into the mental health of police and emergency services nationwide revealed that compared to the general adult population in Australia, first responders have higher rates of psychological distress, suicidal thinking, and diagnosis of mental health conditions. The study found a workforce that is deeply impacted, both by the nature of the work they do and the pressures of the environments in which they work. (Beyond Blue 2018, p. 6).

In the last few years agencies have prioritised mental health and have implemented or scaled up wellbeing interventions, including employee assistance programs/counselling services, mental health literacy/first aid training and app development. Despite substantial research and action in improving mental health and wellbeing in the emergency services sector, translation to real world effects is slow (McCreary 2019). The reasons for this are complex and include the pervasive influence of stigma on help seeking behaviours. An opportunity exists to rethink our approach to mental health and develop prevention and early interventions that aim to avoid mental health injury in the first place.

Lived Experience Networks (LENs) have the potential to inspire and empower individuals to care for their mental health and to promote culture change in our sector. This is because LENs uphold "a wellness model that focuses on strengths and recovery (and) the positive aspects of people and their ability to function effectively and supportively" (Repper & Carter 2011, p.394). A wellness model contrasts with "an illness model, which places more emphasis on symptoms and problems of individuals" (ibid).

Benefits

According to the National Mental Health Commission (Byrne et al 2019, p. 6), lived experience has the following benefits for different stakeholders.

Families and social networks:

- Lived understanding aids rapport and relationships built on connection and trust
- More equitable relationships
- Foster a sense of belonging/ community
- Focus on human rights/ social justice
- Living example of hope
- Increased empathy
- Advocacy
- Mutuality

People accessing services:

- Risk adverse approaches replaced by dignity of risk
- Lived understanding aids rapport and relationships built on connection and trust
- More equitable relationships
- Foster a sense of belonging/ community
- Focus on human rights/ social justice
- Living example of hope
- Increased empathy
- Advocacy
- Mutuality

Benefits for organisations and colleagues:

- Greater recovery understanding/ orientation
- Contribute to more person-directed approaches
- Co-production leads to safer and more accountable services
- Contribute to more inclusive, flexible, resilient work culture
- 'Bridge' of understanding between people accessing services and colleagues in traditional roles

- Reduced need for ongoing formal support and hospitalisation

Evidence for the efficacy of Lived Experience Networks

A review of the evidence helps explain why LENs ae beneficial, and especially how they encourage self-determination, and shared and positive understandings of mental health. Lived experience speakers and representatives have been used to great effect by Mind Australia (2021) to "enhance community understanding of mental ill-health and… reduce stigma and improve knowledge within the Australian public". It's not enough though to say that LENs raise awareness, their true value lies in promoting a recovery-oriented ethos through biographic framing (Kaine 2018). As a narrative mode, speakers describe mental health as a journey that ebbs and flows but can be acted on to manage or transform mental disturbances to a state of wellness. Lived experience stories emphasise that a state of wellness is never fixed for the mind is a dynamic entity that requires attention and care.

LENs can be considered a kind of peer support program because they involve learning how to improve from the examples of others. Indeed, it is the very ordinariness or ability to relate to the speaker which makes lived experience an effective intervention for mental health. Hearing what a regular person – someone like the person listening – has done to get on top of their difficulties elicits an empathic and hopeful response. It inspires the feeling that "if they can do it, so can I" to a greater extent than hearing the exceptional stories of a person the audience does not identify with.

LENs render visible the invisible struggle of mental health experience. Being represented, in turn, legitimises the experience of and gives a sense of connection for people with mental health struggles (Basset, Faulkner, Repper, & Stamou, 2010; Davies, Gray, & Butcher, 2014; Franke, Paton, & Gassner, 2010; Repper & Carter, 2011). Sharing stories of pain and healing inspires hope, a motivating emotion with a strong cognitive component. The science of hope highlights how hope is as much a thought as a feeling and its ability to promote resilience and be beneficial for mental health across contexts and the lifespan (Corn, Feldman & Wexler 2020). Rick Snyder's (1995) model of hope presents how imaging a future that is better than the present motivates action and that which inspires hope lays down cognitive pathways for self-improvement.

The individual who safely shares their mental health journey with others is also advantaged. Specifically, their role gives them the opportunity to play a valuable, unique, and legitimate role in mental illness and suicide prevention. Research on why people are motivated to do suicide-related lived experience found the ability to "share without censure" to be a primary reason (Maple et al 2020a). Another reason is to help others through expanding the knowledge base about suicide prevention and wanting to change services so that others could have a better experience (Maple et al 2020b).

Giving back to your community – as a form of prosocial behaviour - is a well-known to be an activity that boosts wellbeing (Aknin 2019). Lindahl (2018, p. 221) notes that "narrative

practices that draw upon oral narration in an intimate setting to transform vulnerable members of the story-sharing community into 'overcomers'" has therapeutic benefits for the narrator. A compassionate response from an audience can also support the healing process for speakers. Research by the National Suicide Prevention Taskforce (2020) described a common and distressing scenario where, precisely when people are highly distressed and in need of care and understanding, health and other related systems provide disjointed care that is lacking in empathy or else not available.

LENs can be a resource to inform the design of wellbeing programs and services, so they are sensitive to the needs of cohorts, such as emergency service workers and volunteers. While not the focus of this paper, it is worth noting that "lived experience practitioners provide a bridge of understanding to facilitate better understanding of the needs of those accessing services and assist services to provide more effective support". Christine Morgan, the National Suicide Prevention Adviser, has eloquently emphasised this point by stating that "We have no option but to position lived experience knowledge at the forefront of research, policy, and practice. Without it our reforms and service improvements will fall short of what people need and what people deserve" (Byrne 2019, p. i).

Stigma and help seeking

People with mental illness often report mental illness stigma as a central concern that relates to stereotypes and prejudice (Productivity Commission 2020). The misconceptions about mental illness that create stigma further exacerbate conditions by creating social disengagement, exclusion, and a reluctance to seek care. These findings are especially relevant in the emergency services sector where stigma around mental health is high (Beyond Blue 2018) and a key barrier to help-seeking behaviours (Lawrence-Wood et. al. 2021).

The Black Dog Institute recognises the significance and value of working with people with lived experience "to build understanding and reduce stigma and discrimination". By tapping the power of peer support, LENS have the potential to "transform stigma to understanding and transform people from passive recipients of what the medical model and society have always told them was good for them, into allies who see another way" (Beales & Wilson 2015; p. 322).

In addition to communicating the message that individuals can take proactive measures to alleviate psychological distress, anguish and suffering, LENs communicate that people will be supported by colleagues if they experience mental health condition. This function is critically important considering Beyond Blue's (2018, p. 95) finding that self-stigma – stigma surrounding one's own mental health - is stronger than stigma held about others.

There are numerous theories in psychology and sociology to explain the power of lived experience for stigma reduction. In different ways, these understandings hinge on the fact

that talking about that which is typically not spoken of, changes collective perceptions of social reality. Social reality, sometimes called culture, is the dominant way of understanding the world and how people are ordered in relation to it and to each another. Social reality is normative, which is to say it is made up of norms which manifest as expectations we hold of what people can and can't do. Social reality can appear stable, but it is always in flux. Breaking down taboos, such as stereotypes and avoidance of mental illness, is one way that change happens.

The relationship of lived experience speakers to social and cultural change is illuminated by several theories. For example, the theory of role modelling suggests that speaking out on certain issues, under certain conditions, can inspire change in the personal goals and behaviours of others (Morgenroth, Ryan & Peters 2015; Abraham & Michie 2008). From the view of Michele Foucault (2019) lived experience stories shape 'discourse' – the unspoken social rules that create parameters of what can and cannot be said.

Talcott Parson's (1961) understand social change as shifts in thresholds of shame. This resonates with the emotional aspects of stigma, which is motivated by the desire to avoid feelings of shame. If shame drives silence around mental health issues, LENs break this silence which, in legitimating environments, can challenge shame and break down stigma.

Social norm theory also explains why LENs influence a reduction in stigma and promotion of help-seeking. Norms are like the skeleton of culture - they exert a direct and indirect influence over our behaviour by compelling us maintain the status quo for the sake of peace and group cohesion. Speaking out against the grain – such as voicing one's experiences of mental health struggles – is a critical step for changing social norms. This is because it throws up different ideas to what is taken for granted as normal and acceptable (Cislaghi & Heise 2018). When a critical mass of people discusses a topic that is considered private or even impolite, we are on the path to normative change which is to say cultural change (UNFPA 2016)

Responding to a gap

Currently no LEN for the sector in Victoria exists and consultations with stakeholders from 14 emergency management organisations point to the need for a network of people from across the sector to share their lived experience of psychological injury. The evidence reviewed in this paper is in support of ESF's proposal to develop and host a LEN for the entire Victorian emergency service / management sector. In general, the links between LENs and stigma reduction, help-seeking and culture change indicate strong value in building a platform for emergency service personnel to learn how to safely share their stories of wellbeing struggles, coping strategies and recovery journey.

Developing a LEN responds to a key recommendation in Victoria Police's Mental Health Review (2016) to build a Lived Experience library of police officers able and prepared to speak

about their experience. In an environmental scan, Victoria Police identified the Beyond Blue's speaker's bureau as a promising approach. VicPol have also completed some background work in relation to governance and resourcing they are willing to share. Cliff Overton, ESF alumni, would bring to the Network experience as a member of the Beyond Blue speakers bureau.

The ESF Lived Experience Network will draw from the lessons and systems of similar programs in other organisations. LENs have been successfully developed by a range of non-for-profits to deliver educational material and conduct awareness raising activities. Examples of leading mental health organisations who rely lived experience ambassadors or mentors are Sane's peer ambassadors; Suicide Prevention Australia's Lived Experience Network (LEN); Roses in the Ocean Lived Experience Collective; and Beyond Blue's speakers bureau and podcast series.

ESF's Lived Experience Network will also benefit from the emerging body of resources being developed, including the National Mental Health Commission's 'National Lived Experience (Peer) Workforce Development Guidelines', developed in 2020 under Action 29 of the Fifth National Mental Health and Suicide Prevention Plan.

Conclusion

LENs "provide a common-sense, firsthand understanding and approach to surviving and thriving with mental health challenges" (Byrne & Wykes 2020, p.244). As such they present an opportunity to reach people before they hit crisis point providing hope and encouraging help seeking. A LEN for the sector would be a valuable evidence informed prevention and early intervention addition to the existing suite of interventions that exist in agencies to address the mental health and wellbeing challenges of our sector.

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