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SPEAKING OUT

The Global Need for Lived Experience Leadership

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Topic: Common challenges and experiences of the lived experience/peer workforce globally are considered, with an emphasis on ensuring that future developments both protect and promote the unique lived experience perspective. ***Purpose:*** In the Western world, rapid growth in lived experience roles has led to an urgent need for training and workforce development. However, research indicates the roles risk being coopted without clear lived experience leadership, which is often not occurring. In developing countries and in many Western contexts, the lived experience role has not yet been accepted within the mental health workforce. The need for lived experience leadership to guide these issues is highlighted. ***Sources:*** Peer-reviewed research, relevant gray literature, and professional experience in countries where little published material currently exists. ***Conclusions and Implications for Practice:*** A window of opportunity currently exists to maximize lived experience leadership, and that window may be closing fast if broad-based actions are not initiated now.

Keywords: consumers, lived experience leadership, peer work, mental health services, coproduction

One of the most crucial and least recognized elements of the recovery approach is the role of persons with experience of recovery at three levels (Davidson, Ridgway, O'Connell, & Kirk, 2014; Davidson et al., 2007). First, persons diagnosed with mental illness need to be empowered to pursue a life of meaning and purpose, as well as educated to manage their own care—in most services, care management remains the sole purview of the treatment team. At the second level, persons in recovery can inspire hope and provide empathy, advocacy, and assistance navigating the mental health system and the broader community (e.g., peer workers). Third, consistent with the disability rights vision of "nothing about us without us," persons with lived experience of recovery need to occupy senior leadership roles impacting social policy, system management, planning, education, program development, and evaluation. While varying degrees of progress are being made at the first two levels, it is, in our opinion, the third level that is presently the most critical and yet least advanced. Despite notable exceptions, the mental health sector largely lacks formal leadership positions allocated to persons with lived experience of recovery (Health Workforce Australia, 2013). The few senior positions that do exist are dispersed across a vast array of role types and service settings, including government, public, not-for-profit, and private organizations, from metropolitan to rural and remote locations (Byrne, Happell, & Reid-Searl, 2017). Despite diversity across settings and role types, people employed in lived experience positions appear universally to face similar challenges. The focus of this article is the broad lived experience workforce, inclusive of many roles. Reports from North America, Canada, New Zealand, Australia, and the United Kingdom demonstrate common issues regarding workforce development needs, including remuneration, lack of role clarity, career trajectory, risk of cooptation, and poor access to training, supervision, or support (Crane, Lepicki, & Knudsen, 2016; Moran, Russinova, Gidugu, & Gagne, 2013). Limited time frames for lived experience initiatives (Chinman et al., 2015) and limited funding and resources for research (O'Hagan, 2012) inhibit the development of a robust evidence base. In developing countries and in many Western contexts, lived experience roles, such as peer workers, are often not accepted meaningfully by the wider mental health workforce (Davidson, 2015; Silver & Nemec, 2016). This lack of perceived credibility results in discrimination and defensiveness on the part of mental health professionals, as well as frequent professional isolation for peer workers (Ahmed, Hunter, Mabe, Tucker, & Buckley, 2015; Happell et al., 2015; Perkins & Slade, 2012). Although urgent development of a well-prepared, effective workforce is needed, research indicates lived experience roles risk being coopted without clear lived experience leadership (Davidson, 2015). Training and workforce development needs to be underpinned by articulated, agreed ideas of what lived experience work is and what informs it. Currently, there are no formal theories overarching lived experience

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work, identifying what the unique and unified vision is (Davidson, Bellamy, Guy, & Miller, 2012). This lack of training and formal theory creates great disparity in the preparedness of lived experience workers and adds to the lack of credibility in the eyes of some mental health professionals (Cronise, Teixeira, Rogers, & Harrington, 2016; Tobin, Chen, & Leathley, 2002). In a catch-22, this lack of credibility likely inhibits lived experience roles being developed at leadership levels, limiting opportunities for persons with lived experience to advocate for or design widely available training or to conduct research to strengthen theoretical underpinnings.

The Southern Hemisphere: Progress and Barriers

In Australia, the recent development of executive-level lived experience roles in some not-for-profit and public mental health services has led to greater acknowledgment of the value of, and consequently increased priority to employ, lived experience workers. In one example, a lived experience leader assisted the organization to be more aware of evidence on the benefits of lived experience roles, ultimately leading to a 300% increase in designated lived experience roles (Richmond, 2015). This is still an isolated example, and the need for lived experience leadership is most urgent in countries without a strong mental health consumer/survivor movement. Presently, in the Southern Hemisphere, the only countries featuring recovery in national policy are Australia and New Zealand. The remainder of the Southern Hemisphere, including Asia and South America, emphasizes concepts of biological illness and external control of symptoms, predominantly through the use of medication (Deacon, 2013). This is not to say that due to national policy, the service systems in Australia and New Zealand are fully recovery oriented. Recovery-oriented policies and practices are still acknowledged as emergent (Shera & Ramon, 2013; Walker, Perkins, & Repper, 2014). However, the lived experience workforce is particularly struggling to emerge in certain areas of Asia. Where it does exist, such as in Hong Kong and Singapore, tight "control" of peer staff through a benevolent approach is common (Tse, Cheung, Kan, Ng, & Yau, 2012). Japan and China have a very fledging lived experience workforce (Fujita et al., 2010), and this has to operate in a climate that enforces a narrow biomedical model. In Indonesia, a country of 250 million people, there are approximately 20 trained peer supporters. Community mental health is practically nonexistent. The mental health system is based on large institutions, and the few peers work in local community health centers. Indonesia has approximately 700 psychiatrists, and 97% work in the capital, Jakarta. It could be surmised that with the evidence demonstrating the effectiveness of lived experience, particularly peer workers (Myrick & Del Vecchio, 2016), and the proportionately lower cost of training and employing people with lived experience, the lived workforce could play an essential role in mental health recovery in countries with constrained health budgets. However, this would first require identifying and supporting lived experience leaders who could then develop a trained and supervised peer workforce.

Lived Experience Leadership in Recovery Orientation

We argue there is an existing space within the mental health sector where lived experience leaders are best qualified to address critical issues for which professionalized (i.e., traditional) knowledge has not been effective. This may be especially true where mental health professionals have adapted concepts of recovery to fit within medically dominant systems (Shera & Ramon, 2013; Slade, Adams, & O'Hagan, 2012). Unlike some areas within mental health, the concept of recovery is most deeply understood, both on an individual and collective level, by people with a lived experience. Conversely, mental health professions and systems have struggled to embrace recovery (Farkas, 2007), often misinterpreting and "misusing" the concepts (Slade et al., 2014). People with a lived experience can bring clarity and profound, personal understanding of recovery to the broader field (Slade et al., 2012; Vayshenker et al., 2016), when provided opportunities to meaningfully input and collaborate (Cleary, Walter, & Hungerford, 2014).

Collaboration, Coproduction, and Championing

The significance of allies, including a willingness to share and even relinquish power, is crucial to the success of lived experience leadership (Baldwin & Sadd, 2006). Although people with a lived experience began promoting recovery concepts in the 1800s, it was not until the early 1990s and the work of William Anthony (Anthony, 1993) and other allies that governments and systems started to pay attention. Ultimately, these established members of the mental health system championed lived experience devised concepts, while working in collaboration with lived experience leaders, and greatly contributed to transformed priorities and policy in Western nations (Jacobson & Curtis, 2000). Similarly, within coproduction, the joint design and development of mental health initiatives by mental health professionals/policy makers and lived experience workers (Petrakis et al., 2014; Rhodes et al., 2014), power must be shared and the authority of lived experience regarding recovery concepts must be accepted (Perkins & Slade, 2012). There remains a risk of tokenistic participation as long as power is not shared and the lived experience contribution does not have equal authority (Boyle & Harris, 2009). Tokenism is much less likely to occur when people with a lived experience are employed in roles with "real-world" impact, further supporting the need for ongoing development of senior and executive-level lived experience roles (Byrne, Happell, & Reid-Searl, 2015).

Sector Transformation Requires Lived Experience Leadership

Lived experience participation within mental health contributes to the human rights agenda at the heart of the recovery movement (Davidson, 2006; Perkins & Slade, 2012). Persons with lived experience in systemic or educational roles provide a bridge to facilitate better understanding between service providers and those accessing services, contributing to more meaningful service provision and, ultimately, better outcomes for service users (Ostrow & Adams, 2012; Pinches, 2011). Emerging research also suggests lived experience may contribute to less restrictive practice (Greenfield, Stoneking, Humphreys, Sundby, & Bond, 2008) and a reduction in service expenditure (Trachtenberg, Parsonage, Shepherd, & Boardman, 2013). For true system transformation to occur, we argue it is essential for more attention and resources to be allocated to cultivating leadership skills among persons with lived experience of recovery and for opportunities to be created for such

individuals to take on senior-level leadership positions within their respective countries and communities.

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