Irish Journal of Psychological Medicine (2024), 1–3
doi:10.1017/ipm.2024.50

CAMBRIDGE UNIVERSITY PRESS

Perspective Piece

Co-creation and recovery in mental health services: a lived experience perspective

Michael Elwan

Faculty of Business, Justice and Behavioural Sciences, Charles Sturt University, Wagga Wagga, Australia

Abstract

This article explores the shift in mental health recovery from mere symptom management to a holistic approach via the CHIME framework. It delves into the author's experience, beginning with the loss of his father, a war veteran with mental health struggles, at 16, thrusting him into the role of primary caregiver for his mother, who also battled mental health issues and eventually took her own life. These events spotlight the shortcomings of traditional mental health care and the urgent need for empathetic, multifaceted services. Advocating for co-creation in mental health services, the article outlines a transition towards a system that integrates recovery principles through stages from co-ideation to co-evaluation, emphasising holistic, person-centred care. It calls for a reimagined mental healthcare system that respects individual journeys and is rooted in co-creation, signalling a critical move towards systemic change.

Keywords: Recovery-oriented care; co-creation; lived experience; CHIME framework; peer support

(Received 15 March 2024; revised 10 August 2024; accepted 16 September 2024)

Introduction

The transformation of the concept of recovery in mental health from a focus on symptom reduction to a more comprehensive understanding of well-being marks a pivotal shift towards recognising the multifaceted nature of recovery. The CHIME framework – emphasising connectedness, hope and optimism, identity, meaning in life, and empowerment – serves as a testament to this evolution, suggesting that recovery transcends medical metrics to encompass a journey towards holistic well-being (Apostolopoulou *et al.*, 2020). This paradigm shift underscores the importance of addressing not just the clinical dimensions of mental health conditions but also the emotional, social, and existential aspects of individuals' lives.

Transitioning from this broader conceptual framework to the lived reality, my journey began in the shadow of my father's struggles as a war veteran with mental health issues and his death when I was just 16. This event thrusted me into the role of sole carer for my mother, who was also grappling with her own mental health challenges, and whose life tragically ended by suicide over a decade later. These experiences have illuminated the complexities and challenges of providing support within a system still grappling with the legacy of its more traditional, medical-model roots. They have provided me with profound insights into the necessity of care approaches that are both empathetic and accessible, resonating with the CHIME framework's call for a more person-centred practice.

Corresponding author: Michael Elwan; Email: Michael_Elwan@outlook.com

Cite this article: Elwan M. Co-creation and recovery in mental health services: a lived experience perspective. *Irish Journal of Psychological Medicine* https://doi.org/10.1017/ipm.2024.50

Bridging the gaps with co-creation

My personal narrative, marked by caring for loved ones with mental health conditions and facing the loss of family to these struggles, has highlighted the critical need for mental health services to evolve further, ensuring that they not only meet clinical needs but also embrace the holistic needs of service users and their carers.

The potential of co-creation to bridge these gaps cannot be overstated. Although the term "co-creation" is increasingly used across health and community settings, its meaning often remains ambiguous, frequently used interchangeably with related concepts like co-design and co-production without a clear, universally accepted definition (Vargas *et al.*, 2022). This article adopts the definition provided by Pearce *et al.* (2020), which positions co-creation in mental health services as the process of generating new knowledge through the application of various collaborative methods within the delivery of programmes or policies. This definition outlines co-creation as encompassing four collaborative stages: co-ideation, co-design, co-implementation, and co-evaluation. Each stage signifies a step towards creating mental health services that are not only evidence-based but also intricately tailored to meet the multifaceted needs of service users.

Co-ideation involves brainstorming and generating ideas collaboratively between service users, carers, peer workers, service providers, researchers, and mental health professionals, ensuring innovations are grounded in real-world experiences and needs. **Co-design** builds on this, turning ideas into actionable plans and prototypes, with insights from lived experiences directly informing service development. It sees all stakeholders working side by side to create the service or intervention, ensuring the outcomes reflect

service users' needs and build upon their strengths. **Co-implementation** extends the partnership into the delivery phase, with services provided in a manner that respects and utilises the expertise of professionals and those with lived experiences equally. Finally, **Co-evaluation** involves assessing the effectiveness and impact of services collaboratively, ensuring feedback from all stakeholders, especially those with lived experiences, is integral to continuous improvement and refinement.

The synergy between co-creation and the recovery movement, underscoring empowerment, personal growth, and active participation, is particularly resonant with my journey. By championing an environment where service users are co-creators in their care pathways, mental health services can more effectively support the unique recovery journeys of individuals (Senneseth *et al*., 2022). This collaborative ethos not only questions traditional hierarchies within mental health care but also resonates with the CHIME framework's core principles of agency, meaning, and connectedness, encapsulating the essence of a recovery-oriented approach (Kvia *et al*., 2021).

Leveraging personal experience and best practices

Through the lens of my personal experience, coupled with best practices from the field, it is clear that a mental healthcare system reflecting the needs and aspirations of those it serves is possible. This requires ongoing education, transparent communication, and a commitment to re-evaluating and refining co-creation processes to ensure they remain responsive and effective. The involvement of individuals with lived experience as vital contributors to the care process, along with the integration of peer support, underscores the necessity of flexibility, responsiveness, and a commitment to respecting the individuality of each person's journey.

To implement recovery values and principles in the real world and consequently realise a transformative vision for mental health care, the following systemic changes in policy and practice are imperative:

1. **Institutionalising co-creation**: Mandate the active involvement of service users and their carers across all mental healthcare phases, from service conceptualisation to evaluation. Establish formal structures to facilitate co-creation as a standard practice within mental health institutions (Pearce *et al*., 2022 2020).
2. **Investing in peer support programmes**: Enhance financial and logistical support for peer support initiatives, recognising them as essential complements to professional services. This includes funding training programmes, integrating peer roles within mental health teams, and evaluating the impact of peer support (Shalaby and Agyapong, 2020, Storm *et al*., 2020, Richard *et al*., 2022).
3. **Enhancing training on recovery and co-creation**: Broaden the scope of training for mental health professionals to cover recovery principles, the value of lived experience, and co-creation practices. Aim to cultivate more empathetic, person-centred care approaches (Arblaster *et al*., 2023).
4. **Ensuring accessibility and universality**: Guarantee that mental health services are accessible to everyone, addressing barriers related to cost, location, culture, and language. Strive to eliminate disparities in mental healthcare access and quality (Muhorakeye and Biracyaza, 2021).
5. **Promoting continuous evaluation and improvement**: Implement ongoing evaluation mechanisms for mental health services, prioritising feedback from service users to inform improvements and ensure alignment with recovery and co-creation principles (Lin *et al*., 2023).

Achieving an inclusive, compassionate, and effective mental healthcare system requires the concerted efforts and collaboration of every stakeholder within the ecosystem. Each plays a crucial role in transforming the landscape of mental health services:

- **Mental health practitioners:** Essential in fostering empathy and partnership, they should leverage the insights of service users and carers to deliver person-centred care that truly addresses individual needs.
- **Policymakers and funders:** Their role is pivotal in ensuring that mental healthcare frameworks support peer support, value lived experience, and encourage collaborative practices.
- **Service users and carers:** Their advocacy for participatory rights in care decisions is crucial. By contributing their insights and experiences, they help shape services to meet real-world needs and ensure that care delivery is resonant with those it aims to support.
- **Peer workers:** As individuals with lived experience, peer workers bridge the gap between service users and providers, offering unique insights, empathy, and support that foster a more understanding and supportive care environment.
- **Service providers and management:** They play a key role in implementing the principles of co-creation and recovery-oriented care within organisations. Their commitment to amplifying marginalised voices, combating stigma, and promoting mental health literacy is essential for making care more accessible, inclusive, and equitable.
- **Researchers and academics:** Through continuous investigation into the effects of recovery-oriented care and co-creation, they guide best practices and inform policy, ensuring that mental health services are based on evidence that reflects the complexity of human well-being.
- **Universities:** As institutions of learning and research, universities are vital in educating the next generation of mental health professionals. They also contribute to research that drives innovation in mental healthcare practices and policies.

These stakeholder groups are interconnected, with their roles complementing and reinforcing one another to advance a unified vision for mental health care that is recovery-oriented, co-created, and deeply respectful of each individual's journey.

The path towards a more inclusive, effective, and compassionate mental healthcare system is both challenging and rewarding. It requires us to question long-held assumptions, to embrace uncertainty, and to commit to continuous learning and adaptation. Yet, the promise of a mental health system that truly supports recovery, values lived experience, and thrives on co-creation is a goal worth striving for.

Financial support. This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Competing interests. The author declares none.

Ethical standard. The author asserts that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

https://doi.org/10.1017/ipm.2024.50 Published online by Cambridge University Press

References

Apostolopoulou A, Stylianidis S, Issari P, Chondros P, Alexiadou A, Belekou P, Giannou C, Karali EK, Foi V, Tzaferou F (2020). Experiences of recovery in EPAPSY's community residential facilities and the five CHIME concepts: A qualitative inquiry. *Frontiers in Psychiatry* **11**, 1–12.

Arblaster K, Mackenzie L, Buus N, Chen T, Gill K, Gomez L, Hamilton D, Hancock N, McCloughen A, Nicholson M, Quinn Y, River J, Scanlan JN, Schneider C, Schweizer R, Wells K (2023). Co-design and evaluation of a multidisciplinary teaching resource on mental health recovery involving people with lived experience. *Australian Occupational Therapy Journal* **70**, 354–365.

Kvia A, Dahl C, Grønnestad T, Frahm Jensen MJ (2021). Easier to say 'recovery' than to do recovery: Employees' experiences of implementing a recovery-oriented practice. *International Journal of Mental Health and Addiction* **19**, 1919–1930.

lin E, Harris H, Black G, Bellissimo G, Di Giandomenico A, Rodak T, Costa-dookhan KA, R Shier, Rovet J, Gruszecki S, Soklaridis S (2023). Evaluating recovery colleges: A co-created scoping review. *Journal of Mental Health* **32**, 813–834.

Muhorakeye O, Biracyaza E (2021). Exploring barriers to mental health services utilization at Kabutare district hospital of Rwanda: Perspectives from patients. *Frontiers in Psychology* **12**, 1–13.

Pearce T, Maple M, McKay K, Shakeshaft A, Wayland S (2022). Co-creation of new knowledge: Good fortune or good management? *Research Involvement and Engagement* **8**, 1–13.

Pearce T, Maple M, Shakeshaft A, Wayland S, Mckay K (2020). What is the co-creation of new knowledge? A content analysis and proposed definition for health interventions. *International Journal of Environmental Research and Public Health* **17**, 1–18.

Richard J, Rebinsky R, Suresh R, Kubic S, Carter A, Cunningham JEA, Ker A, Williams K, Sorin M (2022). Scoping review to evaluate the effects of peer support on the mental health of young adults. *British Medical Journal Open* **12**, 1–8.

Senneseth M, Pollak C, Urheim R, Logan C, Palmstierna T (2022). Personal recovery and its challenges in forensic mental health: Systematic review and thematic synthesis of the qualitative literature. *British Journal of Psychiatry Open* **8**, 1–15.

Shalaby RAH, Agyapong VIO (2020). Peer support in mental health: Literature review. *Journal of Medical Internet Research Mental Health* **7**, 1–14.

Storm M, Fortuna KL, Brooks JM, Bartels SJ (2020). Peer support in coordination of physical health and mental health services for people with lived experience of a serious mental illness. *Frontiers in Psychiatry* **11**, 1–7.

Vargas C, Whelan J, Brimblecombe J, Allender S (2022). Co-creation, co-design, co-production for public health: A perspective on definition and distinctions. *Public Health Research & Practice* **32**, 1–7.

https://doi.org/10.1017/ipm.2024.50 Published online by Cambridge University Press