Irish Journal of Psychological Medicine (2025), 1–3
doi:10.1017/ipm.2025.10148

CAMBRIDGE
UNIVERSITY PRESS

Historical Paper

Civil society as an untapped ally in fighting stigma against people with co-occurring mental illness and substance use disorders: an opinion paper

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Abstract

The co-occurrence of mental illness and substance use disorders (SUDs) presents a significant public health challenge with affected individuals facing compounded stigma that leads to poor health outcomes, social exclusion, and systemic neglect. Despite growing recognition of stigma as a social determinant of health in people with comorbid mental illness and SUDs, current responses remain largely confined to clinical and academic settings. This article argues that civil society, particularly groups led by individuals with lived experience, represents an underutilized yet powerful force in combating stigma. Drawing from historical movements such as HIV/AIDS activism and contemporary examples from peer-led movements, we highlight how civil society organizations (CSOs) have reshaped public discourse, influenced policy, and fostered inclusive research. We examine emerging efforts in low resource settings and explore the transformative potential of digital civil society spaces. We advocate for a shift in stigma reduction paradigms to those that center lived experience, supports cross-sectoral collaboration, and recognizes both physical and digital civil society as essential to inclusive and sustainable change. To addressing the complex and intersecting stigmas associated with comorbid mental illness and SUDs, we recommend investing in CSOs, especially those grounded in participatory, culturally relevant approaches, particularly in low- and middle-income settings.

Keywords: Civil society; comorbidity; mental health; stigma; substance use disorders

(Received 2 April 2025; revised 15 October 2025; accepted 13 November 2025)

Introduction

The dual burden of co-occurring substance use disorders (SUDs) and mental illness (also referred as dual diagnosis and comorbidity) presents one of the most pressing challenges in global health, with an estimated 35 million people suffering from SUDs and approximately 50–80% of these patients presenting with comorbid mental illnesses (Kingston *et al.* 2017, Montanari, 2024). Individuals with co-occurring SUDs and mental illnesses experience a unique intersection of multiple stigmatized identities: one associated with mental illness and the other with SUD, which contributes to poor health outcomes, social exclusion, and systemic discrimination (Henwood *et al.* 2013, Polcin, 2016). While progress has been made in amplifying the need to highlight stigma as a social determinant of poor health in people with mental ill health and substance use, many of these efforts operate within clinical or academic environments (Thornicroft *et al.* 2022).

Historical role of civil societies in addressing stigma

Civil societies, especially those led by or run in collaboration with people with lived experience, offer a powerful but often unrecognized avenue to transform how we tackle stigma against people with comorbid mental illness and SUDs. Drawing from historical examples of how civil societies transformed how we perceived, treated, and supported individuals with highly stigmatized conditions such as HIV/AIDS, current efforts to destigmatize comorbidities in mental illness and SUD can borrow from the lessons learned through these movements. For example, to fight state inaction and societal stigma against people with HIV/AIDS, the Treatment Action Campaign in South Africa, founded in 1998, mobilized public advocacy and legal action, which contributed to a shift in the perception and public health response to HIV from a private affliction to a public health and human rights issue (Robins, 2006). Similarly, for non-communicable diseases that affect the brain, such as epilepsy, grassroots organizations led by people with lived experience, such as the International Bureau Against Epilepsy (IBE), have played a key role in changing policy to tackle stigma. For example, in 2022, the World Health Assembly adopted the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders as a result of years of advocacy efforts

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Cite this article: Atieno-Bitta M, Merali Z, Mabia C, and Kouimtsidis C. Civil society as an untapped ally in fighting stigma against people with co-occurring mental illness and substance use disorders: an opinion paper. *Irish Journal of Psychological Medicine* https://doi.org/10.1017/ipm.2025.10148

by IBE in collaboration with other decision-making stakeholders in governments and other players such as scientists (Guekht *et al.* 2021, Kanmounye *et al.* 2022).

Civil societies in mental health, SUD, and comorbidity

Despite these successes, civil society remains marginal in advocacy related to SUD, such as harm reduction (O'Gorman & Schatz, 2021) and in mental ill health, where interventions are often top-down and clinically oriented (Thornicroft *et al.* 2022). This gap is even more pronounced in dual diagnosis contexts, where individuals face compounded stigma and systemic neglect (Corrigan *et al.* 2014). The limited integration of civil society in responses to mental illness, SUDs, and comorbidity underscores the need to re-evaluate how legitimacy, expertise, and leadership are defined in stigma reduction initiatives.

Civil society groups, often closer to the realities of people living with co-occurring conditions than institutional actors, can play a critical role in advocating for policies and practices that stop stigma. They are embedded in communities, culturally attuned, and nimble enough to address the social determinants of stigma in ways that top-down interventions cannot.

Examples of globally impactful civil society movements addressing mental ill health include the *Global Mental Health Peer Network* (GMHPN) (Sunkel, 2021), which has emerged as a leader in focusing on lived experience in research and advocacy. With its headquarters in South Africa, GMHPN operates across multiple countries, empowering individuals with mental ill health to participate in shaping mental health systems. Through its advocacy efforts, network members are actively shaping the discourse on stigma in various ways, including by participating in research (Thornicroft *et al.* 2022) and organizing platforms such as global scientific conferences to foster dialogue on stigma. Regional efforts are underway to enhance civil society's involvement in mental health advocacy. For example, the Africa Centres for Disease Control and Prevention (Africa CDC) is leading an initiative to map civil society organizations (CSOs) engaged in mental health activities. This initiative aims to create networking opportunities and improve access to resources, including small grants, to help these organizations achieve their goals (https://www.mhinnovation.net/mapping-mental-health-csos-africa. However, a critical consideration is the risk that initiatives such as those by the CDC may inadvertently institutionalize civil society operations. By their very nature, these entities are intended to disrupt and transcend the institutional barriers that often hinder effective responses to complex social and health challenges (Banks *et al.* 2015).

The way forward

To make meaningful progress in reducing stigma in comorbid mental illness and SUDs, we must reframe stigma as a political and public health challenge and not merely a clinical or individual concern. We must also rethink our global health stigma reduction paradigms and fund CSOs as central components of these efforts while embedding lived experience in all aspects of research, program design, and policy. This should be done in the context of cross-sectoral partnerships between stakeholders in mental ill health and SUDs, such as governments, community organizations, and academic entities. Investment in CSOs should prioritize those that use participatory approaches that are contextually sensitive and culturally grounded, particularly in low and middle-income settings, which bear a disproportionately large burden of these disorders.

As the digital era reshapes health communication, we must rethink the traditional notion of "grassroots." Movements are no longer limited to geographical spaces such as neighborhoods or villages but are now emerging from hashtags, blogs, and livestreams (Lupton, 2014). Crucially, we must now recognize the internet as a legitimate site of civil society due to its ability to host large groups of individuals with shared interests who would otherwise be isolated due to geographical limitations. For individuals isolated or stigmatized in their physical environments, online platforms provide spaces for visibility and opportunities for collective voice. These digital spaces, from peer-led forums to decentralized mental health movements, operate with the same grassroots ethos as physical collectives, yet leverage the scale and immediacy of networked technologies (Naslund *et al.* 2016). Online communities have shown the capacity to shape public discourse, hold institutions accountable, and offer real-time support to those affected by mental health and substance use conditions (Smith-Merry *et al.* 2019).

Additionally, technological advancements such as artificial intelligence (AI) have provided powerful tools to support, but not replace, stigma reduction efforts. For example, AI-powered natural language processing can help identify stigmatizing language in media or healthcare settings (Oscar *et al.* 2017) while digital platforms can facilitate non-judgmental peer support (Strand *et al.* 2020). However, these technologies are only as effective as the values embedded in their design. Without the involvement of civil society and lived experience advocates, there is a real risk that AI will reproduce the biases it aims to challenge.

These developments challenge us to expand our understanding of civil society beyond the physical to include the digital infrastructures. It also challenges us to re-evaluate how we assign legitimacy in global health. The current practice is to relegate CSOs to the margins, often labeled as "consultants," and assign them ancillary roles in advocacy, such as storytelling, yet evidence suggests that CSOs can play a transformative role in tackling stigma. As stakeholders in mental ill health and SUDs, we must ask ourselves: who is already doing the work, and how can we support and amplify them? The future of stigma reduction in comorbid mental ill health and SUDs lies in capitalizing on collective courage, centering efforts on lived-experience voices and utilizing the technological advancements that dismantled exclusionary barriers such as geography and limited data access. Civil society holds that courage; it is time we recognized it.

Funding statement. The authors received no specific funding for this work.

Competing interests. The authors declare no competing interests.

Ethical standards. This opinion piece does not involve original research with human participants or animals. As such, ethical approval was not required. The authors declare that the views expressed are their own and based on professional expertise and publicly available sources.

References

Banks N, Hulme D and Edwards M (2015) NGOs, states, and donors revisited: Still too close for comfort? *World Development* **66**, 707–718.

Corrigan PW, Druss BG and Perlick DA (2014) The impact of mental illness stigma on seeking and participating in mental health care. *Psychological Science in the Public Interest* **15**, 37–70.

Guekht A, Brodie M, Secco M, Li S, Volkers N and Wiebe S (2021) The road to a World Health Organization global action plan on epilepsy and other neurological disorders. *Epilepsia* **62**, 1057–1063.

Henwood BF, Hsu H-T, Dent D, Winetrobe H, Carranza A and Wenzel S (2013) Transitioning from homelessness: A “fresh-start” event. *Journal of the Society for Social Work and Research* **4**, 47–57.

Kanmounye US, Abu-Bonsrah N, Shlobin NA and Djoutsop OM (2022) The World Health Organization’s intersectoral global action plan on epilepsy and other neurological disorders 2022–2031. *Neurosurgery* **90**, e201–e203.

Kingston RE, Marel C and Mills KL (2017) A systematic review of the prevalence of comorbid mental health disorders in people presenting for substance use treatment in Australia. *Drug and Alcohol Review* **36**, 527–539.

Lupton D (2014). *Digital Sociology*. Routledge.

Montanari L (2024) Comorbidity of substance use and mental disorders in Europe. *European Journal of Public Health* **34**, ckae144. 524.

Naslund JA, Aschbrenner KA, Marsch LA and Bartels SJ (2016). The future of mental health care: peer-to-peer support and social media. *Epidemiol Psychiatr Sci* **25**, 113–122.

O’Gorman A and Schatz E (2021) Civil society involvement in harm reduction drug policy: reflections on the past, expectations for the future. *Harm Reduction Journal* **18**, 17.

Oscar N, Fox PA, Croucher R, Wernick R, Keune J and Hooker K (2017) Machine learning, sentiment analysis, and tweets: An examination of Alzheimer’s disease stigma on Twitter. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences* **72**, 742–751.

Polcin DL (2016) Co-occurring substance abuse and mental health problems among homeless persons: Suggestions for research and practice. *Journal of social distress and the homeless* **25**, 1–10.

Robins S (2006) From “rights” to “ritual”: AIDS activism in South Africa. *American Anthropologist* **108**, 312–323.

Smith-Merry J, Goggin G, Campbell A, McKenzie K, Ridout B and Baylosis C (2019) Social connection and online engagement: insights from interviews with users of a mental health online forum. *JMIR Mental Health* **6**, e11084.

Strand M, Eng LS and Gammon D (2020) Combining online and offline peer support groups in community mental health care settings: a qualitative study of service users’ experiences. *International Journal of Mental Health Systems* **14**, 39.

Sunkel C (2021) The global mental health peer network: the role of persons with lived experience with mental health conditions. In *Innovations in Global Mental Health*. Springer, pp. 1497–1513.

Thornicroft G, Sunkel C, Alikhon Aliev A, Baker S, Brohan E, el Chammay R, Davies K, Demissie M, Duncan J, Fekadu W, Gronholm PC, Guerrero Z, Gurung D, Habtamu K, Hanlon C, Heim E, Henderson C, Hijazi Z, Hoffman C and Winkler P (2022). The Lancet Commission on ending stigma and discrimination in mental health. *The Lancet* **400**, 1438–1480.