

A best practice of developing a global lived experience organisation



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Introduction

The Global Mental Health Peer Network (GMHPN) is an international non-profit organisation committed to empowering people with lived experience (PWLE) of mental health conditions to become catalysts for change on a global scale. Founded by its Chief Executive Officer (CEO), who is living with schizophrenia, GMHPN was born out of a mission to strengthen the voices of those marginalised in conversations about mental health and what affects them directly or indirectly.

Global Mental Health Peer Network was officially launched at the Movement for Global Mental Health's 5th Global Mental Health Summit in 2018 in South Africa. Despite being in its early stages, the organisation quickly evolved from a fledgling initiative into a respected international entity, recognised for its expertise in lived experience and its significant contributions to shaping the global mental health landscape.

From its inception, GMHPN has been driven by a powerful vision: 'to empower those with lived experience of mental health conditions to become influential advocates and change-makers, actively reshaping global mental health narratives and policies'. This unifying vision has been instrumental in rallying support and driving meaningful action within the mental health community worldwide.

Professor Swartz has dedicated his work to influencing national and global mental health discourse, emphasising that effective mental health policy cannot be designed in a government office devoid of the voices of those it impacts. He strongly supports the inclusion of lived experience in policymaking to create more pragmatic, accessible and compassionate services. He stands by the notion that systems are built not just for people but with them.

The impact of his lifelong advocacy is profound and has contributed to a growing movement in South Africa where organisations led by PWLE are gaining traction and respect. It has encouraged a generation of researchers and clinicians to approach their work with greater cultural humility and a deeper sense of ethical responsibility.

Professor Swartz's work reminds us that mental health is not a puzzle to be solved by experts alone, but a deeply human experience to be understood collectively. By advocating for the inclusion of lived experience, he has championed a more democratic, equitable and ultimately effective vision for mental health, one where every voice is heard, and every story is considered essential to the map.

This is how GMHPN's work has been grounded in strong principles and a solid foundation that supports and advocates for a human rights-based approach to mental health, dignity, rights and inclusion of all individuals. It stands firm in its commitment to advocate for an integrated and holistic approach to mental health care that combines medical, social and human rights models to address the complexity of mental health conditions. Committed to upholding international treaties and human rights instruments, GMHPN holds governments and stakeholders accountable for protecting the rights of persons with lived experience. The key thread that calls for action in transforming mental health care is GMHPN's emphasis on the value of lived experience expertise, recognising both its experiential and monetary significance in shaping effective, empathetic and cost-efficient mental health initiatives that truly reflect the needs of those affected.

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Reframing mental health through lived experience inclusion

Literature supports the critical importance of forming strong partnerships between professionals, academic institutions and PWLE to advance mental health research, policy and practice. Such collaborations are essential for creating more effective, inclusive and sustainable mental health interventions. Lived experience expertise provides unique insights that complement professional and academic knowledge, ensuring that solutions are grounded in the realities of those they aim to serve (Slade et al. 2012). This partnership model fosters co-production, where all stakeholders contribute equally, leading to more relevant and impactful outcomes (Gillard et al. 2010).

Professor Swartz has consistently argued that knowledge about mental health does not flow one way, from the academy to the community. Instead, he champions a model where knowledge is co-created. This means involving PWLE not as passive 'subjects' of research, but as active collaborators, helping to define research questions, interpret data and implement findings. This approach transforms research from a potentially extractive process into a participatory and empowering one.

Research highlights that involving PWLE in decision-making processes improves the quality and acceptability of mental health services. For instance, their participation in service design and delivery has been shown to enhance user satisfaction and engagement, as services become more aligned with the needs and preferences of those using them (Simpson, House & Barkham 2014). Additionally, lived experience perspectives challenge stigma and promote a deeper understanding of mental health conditions, which is crucial for reducing discrimination and fostering social inclusion (Corrigan et al. 2012).

Academic institutions benefit from these partnerships by gaining access to rich, real-world data that enhances the relevance and applicability of their research. Collaborative projects that include lived experience voices are more likely to address gaps in knowledge and produce findings that can be effectively translated into practice (Beresford 2013). Furthermore, such partnerships promote capacity building and empowerment among PWLE, enabling them to contribute meaningfully to the mental health field (Faulkner & Kalathil 2012).

By creating platforms for lived experience stories and taking them seriously as a form of evidence, Professor Swartz directly challenges the stigma and silence that so often shroud mental health conditions. When a person's lived experience is valued, their humanity is affirmed.

Through interaction with PWLE, professionals gain a deeper understanding of the complexities of mental health conditions, which can improve their practice and foster more empathetic care. Collaborative approaches also

encourage reflective practice, where professionals critically evaluate their methods and assumptions, leading to continuous improvement in service delivery (Russo & Beresford 2015).

Literature confirms that strong partnerships between professionals, academic institutions and PWLE are not only beneficial but necessary for advancing mental health outcomes. These collaborations ensure that interventions are evidence based, contextually relevant and person centred, ultimately leading to more equitable and effective mental health systems.

Methodology of Global Mental Health Peer Network's function

Global Mental Health Peer Network's methodology focuses on empowerment and capacity-building through targeted activities, including peer-to-peer mentorship, knowledge sharing and support. This aims to cultivate and elevate a cohort of Experts By Experience. Global Mental Health Peer Network goes a step further by incorporating PWLE into its Experts By Experience Consultancy Service, creating an additional structure that not only empowers its members but also supports their economic development through consultancy opportunities. By harnessing the lived experience expertise, GMHPN cultivates active engagement of PWLE as pivotal collaborators in advancing both local and global mental health objectives.

The significance of lived experience expertise in shaping policy, practice and procedural change in global mental health is accepted without contention. Supported by a strong evidence base, international human rights instruments and global health and development frameworks, there is a clear obligation to ensure the meaningful and authentic involvement of PWLE. It is through this that GMHPN has positioned itself to establish sustainable partnerships with stakeholders and allies to support and guide efforts to meaningfully and authentically include PWLE in global mental health.

Evolving in the changing mental health landscape

In a rapidly evolving world and a mental health landscape that demands adaptation to ongoing advancements in science, policy and practice, it has been essential for GMHPN to stay ahead of the curve. Global Mental Health Peer Network's work aligns with Professor Swartz's approach that is deeply rooted in the principles of social justice, recognising that a purely biomedical model, which frames mental health conditions solely as a brain-based disorder to be medicated, is insufficient. It risks erasing the person behind the diagnosis, ignoring the profound impact of context, culture, poverty and stigma.

When GMHPN first emerged in 2018, its primary focus was on advocating for the inclusion of lived experience

perspectives in mental health discourse. Initially, the network sought to amplify the voices of PWLE and promote their active participation in decision-making processes. Over time, however, GMHPN expanded its advocacy efforts to highlight not only the experiential value but also the monetary worth of lived experience expertise in mental health initiatives. Recognising the profound contributions and impact of PWLE, the network shifted its focus towards advocating for fair and equitable compensation and recognition of their expertise (see Figure 1).

In January 2025, GMHPN co-produced a remuneration framework aimed at accelerating progress in the equitable and ethical remuneration of lived experience expertise in global mental health, with funding support generously provided by Kokoro and Vitrol Foundation. Global Mental Health Peer Network's remuneration framework offers a practical approach to ensuring 'Equal Pay for Work of Equal Value' for lived experience roles, aligning with global laws, guidelines, strategies, and collective advocacy efforts.

Today, GMHPN stands as a critical resource for stakeholders seeking guidance on how to authentically and effectively integrate lived experience perspectives into mental health policies, programmes and practices. Through its advisory role, GMHPN continues to champion the meaningful inclusion and empowerment of PWLE, ensuring lived experience voices shape the future of the global mental health landscape.

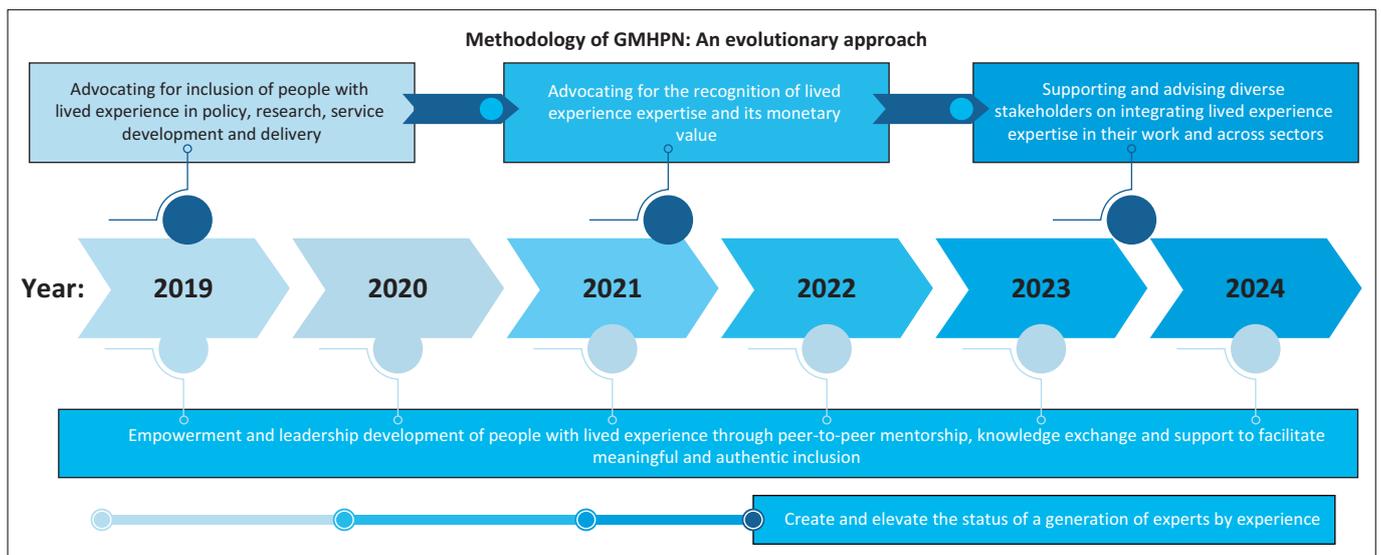
Operational structure

Global Mental Health Peer Network embarked on its journey as an innovative concept, initially lacking a clearly defined operational framework. This required ongoing adjustments

as the organisation progressed. Through this process, the organisation identified its our strengths and areas of greatest influence, concentrating our efforts accordingly.

Seven units currently exist in the organisation: Global Mental Health Peer Network units are crafted to optimise efficiency, enhance productivity and achieve high-quality outcomes that resonate with our overarching vision and objectives:

- **Experts By Experience Consultancy Services (EbE):** Through our EbE unit, we harness the transformative power of lived experience expertise by collaborating with diverse sectors across society. Together with our country leaders, we work to elevate mental health and well-being, driving meaningful change in policies and practices to create a more inclusive, empathetic and hopeful future.
- **Peer-to-Peer Mentorship, Education, Empowerment and Development (P2P):** The P2P unit is a dynamic platform to grow and lead in global mental health advocacy, through tailored mentorship programmes, educational initiatives and skill-building opportunities. By cultivating a supportive and enriching environment, the P2P unit aims to develop a network of empowered advocates who play a pivotal role in influencing mental health narratives and policies across the globe.
- **Benchwarmers Peer Support (PS):** The PS unit promotes mental health and well-being within our lived experience community. Through peer-to-peer support, this unit provides a safe and empathetic space where members can openly share their experiences, challenges and triumphs in navigating mental health journeys. Rooted in solidarity and understanding, the PS unit is instrumental in building a supportive network within GMHPN, where people uplift and empower one another. Together, we strengthen community bonds, cultivate resilience and adopt a culture of compassion and shared understanding.



GMHPN, Global Mental Health Peer Network.

FIGURE 1: Methodology of Global Mental Health Peer Network: An evolutionary approach.

- **Young Agents for Change (YA4C):** Global Mental Health Peer Network's YA4C unit recognises the pivotal role of young people as catalysts for transformation in mental health. This unit is dedicated to empowering, developing and supporting its young change agents, ensuring they have a significant voice in both global and local discussions and decision-making platforms. We believe in encouraging young people to become the next generation of leaders who will contribute to positive shifts in mental health paradigms.
- **Communications and Awareness (C&A):** The C&A unit at GMHPN serves as a dynamic platform to elevate the voices of PWLE in the public domain. Through strategic communication, we strive to share authentic lived experience narratives, creating awareness, understanding and meaningful change in the mental health landscape. Through the C&A unit, the organisation drives initiatives that highlight the power of social contact in combating stigma and discrimination, which continue to plague the mental health field.
- **Focused Initiatives (FI):** Global Mental Health Peer Network's FI unit is committed to spearheading high-impact initiatives that are innovative and advance mental health and promote the integration of lived experience expertise into policy and practice. By focusing on strategic projects, this unit works to create a lasting and transformative impact on the global mental health landscape:
 - **From Recognition to Realisation: Equal Pay for Work of Equal Value – Lived Experience Expertise in Global Mental Health:** Global Mental Health Peer Network developed a remuneration framework to address the significant gaps in guidance on fair and equitable compensation for lived experience expertise in mental health policy, research and services. Little to no publicly available, evidence-based structure that standardises remuneration for the contributions of PWLE exists, despite their growing role in shaping mental health initiatives. Additionally, global stakeholders often lack clear direction on how to integrate and fairly compensate lived experience engagement and consultation within their work and projects. This framework aims to provide a structured and equitable approach to recognising and valuing the impact of lived experience expertise, ensuring that individuals are compensated fairly for their contributions while supporting meaningful and authentic involvement in the mental health sector.
 - **Countdown Global Mental Health 2030:** In partnership with Stellenbosch University, through Professor Leslie Swartz, GMHPN embarked on an initiative to conduct an annual global survey to track progress in key areas such as reducing stigma and discrimination, improving the availability, accessibility and quality of mental health services, integrating lived experience expertise into policy and service development and advancing legal frameworks and human rights in mental health. Partnering with Professor Swartz is crucial as it lends immense academic rigour, credibility and global standing to the

initiative. His decades of pioneering research on stigma, discrimination and the ethics of mental health ensure the survey is methodologically sound, and its findings are authoritative. Furthermore, Professor Swartz's lifelong advocacy for centring lived experience legitimises the GMHPN's mission within academic and policy circles.

- **Operational Development and Sustainability (OD&S):** The OD&S unit serves as a mechanical component of the organisation and is focused on ensuring transparency, sustainable growth and innovation. Committed to maintaining its global reputation, GMHPN continuously adapts to emerging developments and evidence, ensuring that the organisation evolves in step with the ever-changing mental health landscape.

One critical aspect of the structure of GMHPN, constituted by a large group of people from diverse backgrounds, is having a team that sees beyond people's differences and sees the potential and value of each individual. To truly harness the best in every person, there cannot be any power imbalances within any structure of the organisation, regardless of anyone's title within the organisation. Based on this, GMHPN is a community for PWLE that enables every member to thrive.

Strengths

A key strength of GMHPN is its unwavering commitment to inclusivity. The organisation actively welcomes and celebrates individuals from diverse backgrounds, cultures and lived experiences. This inclusive approach cultivates a profound sense of belonging, ensuring that GMHPN authentically represents the global community it serves. The best part of being involved in GMHPN ...:

'Being able to connect with peers globally for mutual learning and collaboration.'

'Feeling that I belong to a special and precious family.'

'Meeting peers who are doing amazing work and studying inspires me to be my best self.'

Global Mental Health Peer Network is proud to be a 100% lived experience-led organisation, fully governed and operated by individuals living with mental health conditions. Bringing together members from all world regions, GMHPN provides a platform for sharing insights and recommendations that drive meaningful change in global mental health. Its expertise is rooted in firsthand experiences of navigating mental health difficulties and systems that often lack comprehensive, person-centric care. By leveraging this unique expertise, GMHPN and its members have the power to challenge and reshape the status quo. Grounded in the proven value of lived experience, GMHPN integrates its expertise into research, policy, service development, stigma reduction and the training of current and future healthcare professionals. The impact of this approach is evident across multiple levels,

reinforcing the vital role of lived experience in shaping mental health initiatives.

With its presence across all world regions, GMHPN has established connections, partnerships and networks with PWLE and key stakeholders dedicated to advancing national and global mental health agendas. This extensive reach enables the organisation to facilitate knowledge exchange, promote best practices and establish collaboration, driving progress in mental health worldwide.

Professor Swartz is a highly regarded partner who has gained respect among the lived experience community for his persistent advocacy that has been less about a radical overthrow and more about a profound, necessary correction: the insistence that the expertise of lived experience is not merely an addendum to mental health work, but its very core.

Work and impact

With a global reach extending across nearly 70 nations, the GMHPN connects a diverse international community of peers. The organisation utilises a strategic digital footprint, hosting peer-led webinars, targeted social media campaigns, online resources and virtual support networks to democratise access to peer expertise. This effort is central to addressing stigma and promoting person-centred care in countries of all income levels. The success of this approach is evidenced by its empowerment and mentorship programme, which has supported a cohort of nearly 200 PWLE. The programme demonstrates a strong commitment to inclusion, with beneficiaries comprising 63% women, 14% youth, 25% who identify as LGBTQIA+ and 68% from low- and middle-income countries.

Global Mental Health Peer Network places a strong emphasis on empowering PWLE to step into leadership roles. This empowerment serves as a powerful catalyst for change and self-advocacy, equipping individuals with the skills and confidence to lead both within the organisation and in broader global contexts.

An open-door policy and effective communication are crucial to establish trust, honesty and respect and to create a unity that is able to drive change together:

'Not only is the GMHPN family very helpful, but they are also tremendously responsive and supportive. Our contributions are valued. I consider this community a safe community for growth. Another point I want to add is that cross-cultural perspectives on mental health add value to our learning curve. They are a key asset for personal development and growth and definitely give me a sense of belonging.'

Global Mental Health Peer Network encourages PWLE to identify deficiencies in the mental health system and accessibility barriers in community living and to share their

ideas and solutions on matters that affect their mental health and well-being. The principle of 'nothing about us, without us' is crucial to advancing inclusive, effective and person-centred approaches. The firsthand insights of PWLE provide a unique and invaluable perspective that can inform policies, practices and services, ensuring they are more responsive, empathetic and impactful. By actively involving those with lived experience, GMHPN not only empowers individuals to take ownership of their narratives but also challenges stigma and promotes a culture of understanding and respect. This collaborative approach enriches innovation, drives meaningful change and ultimately leads to better mental health outcomes, as solutions are rooted in the real-life experiences and needs of those they aim to serve.

Collaboration is at the heart of GMHPN's approach. Over the past 3 years, the organisation has partnered with over 150 initiatives and projects, working alongside a diverse range of stakeholders, including international non-profits, civil society organisations, donors and philanthropic entities, academic and research institutions, large-scale research projects, private sector companies, governments and international agencies. These collaborations have centred on leveraging lived experience expertise, with GMHPN members actively contributing to these efforts.

Much of this collaborative work is conducted through the Experts by Experience Consultancy Services Unit, which coordinates and facilitates lived experience engagement and consultation services to a range of sectors and in various domains across the mental health landscape. This includes hosting mental health workshops and lectures, informing research and research processes, as well as contributing to the development of international reports and strategic plans focused on mental health and human rights.

Global Mental Health Peer Network also provides a safe and inclusive platform for PWLE to share their journeys, experiences and recommendations. This enhances resilience not only among those sharing their stories and perspectives but also among those who draw hope and inspiration from these narratives. Together, these efforts create a solution-focused approach. The best part of being involved in GMHPN ...:

'Opportunities that being in the network have arisen. It has increased my confidence beyond measure. I never thought I would ever be working with the WHO and writing research papers. Being the chairperson for the last term has been an amazing opportunity. I am so happy to be part of the network.'

Global Mental Health Peer Network has been actively involved in the creation of numerous publications, information materials, policies, guidelines and position statements, all developed in collaboration with its members. Through these collaborative efforts, GMHPN has been able to amplify the voices of PWLE of mental health conditions, ensuring that their perspectives are reflected in key mental health discussions and policy developments.

These publications have not only contributed to the global mental health discourse but have also served as valuable resources for policymakers, mental health professionals and other stakeholders seeking to implement more inclusive and effective mental health practices.

The Routledge International Handbook of Disability and Global Health (Sunkel et al. 2024), of which Professor Leslie Swartz is one of the editors, commissioned a chapter that is titled 'Integrating persons with psychosocial disabilities across sectors: meaningful and authentic inclusion in global mental health'. This chapter was co-authored by members of GMHPN and discusses the integration of persons with psychosocial disabilities (lived experience) in global mental health, highlighting the importance of their inclusion in research, policy, service development and delivery. It further highlights that progress remains slow because of obstacles such as stigma, discrimination and inadequate policies. Perspectives from South Africa, India, Denmark and Indonesia illustrate these challenges and showcase some positive advances, such as government initiatives and advocacy efforts. The chapter emphasises the need for meaningful and authentic inclusion, culturally responsive programmes and collaboration across sectors to ensure the rights and well-being of persons with psychosocial disabilities.

Honouring Professor Leslie Swartz

Professor Leslie Swartz has shown a profound dedication to the meaningful and authentic inclusion of PWLE of mental health conditions. At Stellenbosch University, he has pioneered an influential annual workshop that integrates people with mental health conditions into the psychology training curriculum. During his career at Stellenbosch, he brought together individuals with different lived experiences, a family carer and a psychiatrist to address the students by sharing unique journeys and perspectives. This initiative creates a space for students to interact directly with these individuals, using social contact as an educational strategy to combat stigma and foster deeper understanding. Professor Swartz's innovative approach not only enriches student education but also champions dignity, respect and genuine inclusion in mental health training. His work represents a forward-thinking model for reducing stigma through personal engagement and shared experiences.

Through his involvement as editor of the Routledge International Handbook of Disability and Global Health, he continued to honour his dedication to ensuring inclusion of PWLE by providing GMHPN and its members the opportunity to contribute to this publication.

Professor Leslie Swartz stands as a global icon whose career has been dedicated to advocating for and empowering individuals with disabilities, particularly those with mental health conditions. Through his groundbreaking work, compassionate leadership and unwavering commitment to social justice, he has amplified the voices of marginalised communities and championed inclusive policies that have transformed countless lives. His work has not only advanced

academic understanding but also encouraged practical, real-world changes, ensuring that people with disabilities are seen, heard and afforded opportunities to thrive. As an innovator in his field, Professor Swartz's legacy will endure long after his well-deserved retirement, continuing to inspire future generations to pursue equity and dignity for all. His contributions have cemented his status as a beacon of hope and progress in the global fight for disability rights and mental health advocacy.

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Author's contribution

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Data availability

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