



GLOBAL
MENTAL
HEALTH
PEER NETWORK

**Experts
in our own
right**

**Competing for Equality in
Funding and Remuneration:**
*Lived Experience Collaboration,
Engagement and Consultation*

What is our
VALUE?

**GMHPN
REPORT
2022**

Unapologetically Experts By Experience



Introduction

People with lived experience of mental health conditions and their representative organisations have distinctive roles in policy and practice in healthcare, systems strengthening, monitoring and evaluation, and stigma reduction.

Lived experience involvement must be based on principles that enhance diversity, equality and equity and ensure that engagement is meaningful and authentic.

Principles of Engagement

- ☐ *Mutual respect and trust*
- ☐ *Transparency*
- ☐ *Diversity and equality*
- ☐ *Non-discrimination*
- ☐ *Safe space*
- ☐ *Enhance wellness*
- ☐ *Valued contributions*
- ☐ *Non-tokenism*



Purpose of the report

The Global Mental Health Peer Network (GMHPN) is an international lived experience/ peer-led organisation based in South Africa, with representation of more than 140 (one hundred and forty) lived experience advocates from close to 40 (forty) countries across 6 (six) world regions.

The GMHPN, is a fairly young organisation (established in 2018) that prides itself for its 100% lived experience composition throughout the organisation.

To date, it has relied upon donor funding and public donations to finance its operational expenditure, but securing funding has proven to be extremely difficult. We however strive to become a self-sustainable organisation that would not need to solely rely upon funder/ donor support to exist and continue to expand its work. That said, we have established an Experts by Experience Consultancy Services component to our work with the intention of generating income by offering unique expertise to various stakeholders.

Despite global emphasis of the importance of the voices and perspectives of people with lived experience of mental health conditions, the concept of lived experience as service providers and advisors is yet to be fully appreciated and recognised across the world, and is still somewhat undervalued.

As we continue to experience failed attempts in securing funding for both operational and project related grants, we found it necessary to engage with other lived experience/ peer-led organisations and individuals to compare views and experiences on the topic.

The purpose of this report is to inform funders, donors and relevant stakeholders of the experiences faced by lived experience and/or peer-led organisations in a) seeking and securing funding towards their work and b) to advise them on how they could better support lived experience initiatives.

In spite of the growing inclusion of lived experience into engagement and high-level meetings to guide positive change, the concern now is the element of non-remuneration for work done. The objective of sharing the insights in this report is not only to encourage more support for lived experience/ peer-led organisations and those working with people with lived experience, but also **start a meaningful conversation** on this matter.

Problem Statement

The process of decision-making suggests that those who are affected by decisions, should be included in the decision-making itself.

As this pertains mental health, it is relevant to decisions made about mental healthcare and non-health related services and programmes, where said decisions directly affect the service user (positive or negative). This means that the service user (person with lived experience) must be involved in the decisions related to service provision and standards, and the policies and laws that influences accessibility to such care and overall wellbeing. It is worth noting that this statement is not disputed at all but, is in fact, widely supported by the global mental health community.

Notwithstanding the above, the concern remains for the limited recognition of the monetary, and experiential value that the lived experience community contributes to discussions and decision-making on mental health . The experiential value is hardly ever met with monetary value. Consequently, this undermines the lived experiences and expertise of people with mental health conditions and their representative organisations, and jeopardising a truly collaborative and inclusive approach to positive change.



Human Rights Perspective and Call For Action

International human rights instruments call for equality and recognition of the value of all people, including people with psychosocial disabilities/ mental health conditions, towards advancing socio-economic and sustainable development.

The International Covenant on Economic, Social and Cultural Rights speaks of the right to work and remuneration to be fair and equal *"for work of equal value"*.

The UN Convention on the Rights of Persons with Disabilities notes the commitment to *"recognizing the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty"*.

International strategies and related documents emphasise the same by acknowledging the importance of placing people with lived experience of mental health conditions at the centre of policy and practice, thereby ensuring that people with lived experience and their representative organisations are meaningfully and authentically included in engagement and decision-making processes.

WHO World Mental Health Report: Transforming mental health for all (2022) notes that *"People with lived experience are crucial stakeholders in mental health. Their participation is vital to improve mental health systems, services and outcomes. Such participation includes full empowerment and involvement in mental health advocacy, policy, planning, legislation, programme design, service provision, monitoring, research and evaluation"*.

Evidence on the value of lived experience integration into research, policy, service development and delivery, stigma reduction, and training of healthcare professionals have been well documented. The benefits are evident on multiple levels.

GMHPN Challenges: Funders

The GMHPN had been fortunate to receive financial support from a large philanthropic foundation (FPOS), covering the most essential operational expenditures.

Over the past 2 (two) years we have actively been reaching out to funders/ donors with the hope of securing funding to compliment the shortfalls, increase human resources and to further support the organisation's future sustainability. We have however been unsuccessful in these attempts.

Due to a lack of access to funding, we have been unable to appoint additional staff to help ease the increase workload as the GMHPN continues to grow exponentially, while there has been a greater demand for lived experience engagement/ consultation and acknowledgement of an inclusive and collaborative approach to all matters pertaining mental health and human rights.

Among other goals, an important one for GMHPN is to compensate all of our lived experience representatives for their time, commitment and dedication to the GMHPN, but it has been tremendously difficult to reach a sustainable solution to achieve this, due to difficulties in securing funding. The only way we are able to compensate our members is through paid contract work where we were able to involve our members through our Experts by Experience Consultancy Services. This however has not given all members the opportunity to participate in such service delivery activities, since not many paid opportunities exist for experts by experience and most opportunities to consult are not paid.

Since 2022 we have been one of the selected organisations for the Ember Cohort programme which has granted us the opportunity to receive valuable mentorship to strengthen the organisation's capacity to create a strategy that enables us to promote ourselves more effectively, to measure our impact and connect with potential funders/ donors in a highly competitive environment.

This report therefore highlights the experiences of the lived experience community and their representative organisations and to provide insights and recommendations to funders/ donors and stakeholders in the field in relation to lived experience collaboration and engagement.

GMHPN Challenges: Funders

Over the past 2 (two) years, we have submitted more than 30 (thirty) funding applications and letters of enquiry/ expressions of interest, none of which has had a successful outcome.

Out of the 30 (thirty) applications, 24 (twenty-four) responses were received which were general and not directed to the application. In addition, the responses resembled the following:

- Do not have funding
- Do not accept unsolicited applications
- Check website for when applications open
- Do not fall within the strategy (example, funder/ donor website focus on social justice, yet responded that mental health does not fall into social justice)
- Only funding US/UK registered organisation
- Only fund community-based organisations



One (1) response was directly related to the application with reviewer comments received while the remaining submission were never responded to.

As an organisation we [GMHPN] have experienced a number of challenges in securing funding and grants due to restrictions such as but not limited to:

- Funders/ donors having very specific focus areas, e.g. youth within a specific age range, with specific mental health conditions and from specific geographical locations, which eliminates the work of the GMHPN since we work across all age groups, all mental health conditions and within various geographical locations worldwide;
- Criteria are specific to youth, with focus being placed on young people between 14-24 years of age, making it difficult to consider initiatives that fall into this age group as it would involve children (if below 18) and that has another level of ethical complications in terms of consent and safeguarding the mental health and wellbeing of children who participate in projects;

GMHPN Challenges: Funders

- **Limited grant opportunities are available for operational costs** (unrestricted funding), but more available for community-based projects and research related initiatives, and therefore, as an international lived experience advocacy organisation, funding opportunities are extremely limited for the GMHPN;
- Grant amounts are often determined based on the applicant organisation's annual income/ expenditure, meaning that consideration is often **not given to the organisation's need for additional funding to expand its work**, hindering further growth potential;
- Funders/ donors appear to be **reluctant to provide grants to young organisations who have a short financial track record** – thereby creating a situation where it becomes difficult to build a financial track record (without funding);
- Global crises have also been a contributing factor in **funding being diverted from mental health** and related initiatives. This was particularly evident in the early stages of COVID pandemic;
- Despite alignment with funder/ donor strategies and focus areas, some **do not accept unsolicited applications** - unless one has direct contacts or connections within the funder/ donor organisation, making these funding opportunities inaccessible;
- The mental health sector is very competitive when it comes to accessing funding and it would appear, from our experience, that lived experience organisations are less likely to obtain funding compared to academic institutions or organisations not led by people with lived experience – these institutions and organisations who receive funding often have designated roles for lived experience engagement/ consultation into their projects (as collaborators), yet their budget allocation for this collaboration with lived experience organisations/ individuals are often very limited and not aligned with equal compensation for equal work.

GMHPN Challenges: Experts by Experience Consultancy Service

Compensation for stakeholder engagement/ consultation – our cost analysis

As a lived experience organisation, we are frequently requested to collaborate with stakeholders where our role is intended to consult and advise on projects or initiatives throughout phases of development, implementation and evaluation, but our time and expertise are mostly not compensated nor budgeted for in stakeholders' project plans.

In order to derive at a monetary value for our expertise, we have calculated the direct and indirect costs involved (at minimum rates) per person, including staff time and expertise (preparation and participation), and logistical expenses (overheads) for the GMHPN, and this amounts to **R8200** (eight thousand two hundred South African Rand), **equivalent to \$547 and £410** for a one-and-a-half-hour engagement/ consultation session.

On average, we receive a minimum of **40 requests for engagement/ consultations per year** (this excludes recurring meetings of committees and boards that we serve on and conference participation).

- Every year, the **cost to the organisation amounts to more than R500,000/ \$34,000/ £25,000** for our involvement in these engagements/ consultations – where the organisation has to account for the time allocated towards activities outside of its operations.
- **Less than 10%** of these engagements/ consultations **are compensated**.
- Compensation received has mainly been in the form of an honorarium that varied between R1,200 and R2,800 (\$80 and \$186/ £60 and £140), a voucher or data.
- The actual cost to the organisation in comparison to the payment received, has always had a **significant shortfall**.
- Several of these engagement/ consultation sessions, mainly unpaid, involved multiple sessions and extended over 3 (three) hours per session with several additional hours for preparation time allocated – meaning a significant amount of staff time is not funded.

GMHPN Challenges: Experts by Experience Consultancy Service

In 2021, over a 1 (one) year period, our [GMHPN] Experts by Experience Consultancy Services, **generated roughly R150,000/ \$10,000/ £7,500** through 6 (six) contracted assignments, which varied from delivering workshops, reviewing toolkits, developing video materials and providing lived experience perspectives into strategic planning sessions. **More than half of these assignments were paid below our usual fees or actual cost**, due to the clients' limited budget allocation.

As much as we see and **appreciate the importance of collaborating with stakeholders and honour our vital role in bringing the lived experience voices** to discussions and decision-making platforms, we are unable to continue to offer our time and expertise at no cost or at lowered fees, as this will be detrimental to our sustainability.

Therefore, to ensure sustainability for our organisation, it is necessary that the Experts by Experience component of our services becomes part and parcel of all consultations/ engagement requests from all stakeholders seeking lived experience contributions.



Experiences of fellow peers and peer-led organisations

We [GMHPN] have conducted **2 (two) surveys**, one for lived experience peer-led organisations and the other for individuals with lived experience.



In **SURVEY 1**, the GMHPN collected information from a small sample of **organisations** within its network to gather experiences related to seeking and securing funding.

In **SURVEY 2**, we collected information from **individuals** with lived experience to obtain insights from their experiences in engagement and consultation work and how and/or if they had been compensated.

SURVEY 1: Peer-led Organisations

We engaged with lived experience/ peer-led organisations to obtain their experiences in regards to seeking and securing funding towards their work and initiatives. The organisations further shared experiences in relation to compensation for lived experience consultation/ engagement activities.

This engagement was conducted via a survey that was shared with key individuals within the GMHPN contacts and partner organisations.

A total of **16 (sixteen) lived experience/ peer led organisations** (run by persons with lived experience of mental health conditions/ psychosocial disabilities) participated in this exercise, from **across 14 (fourteen) countries** (*Botswana, Cameroon, Ethiopia, Kenya, Malawi, Uganda, Zimbabwe, Indonesia, Singapore, China, England, Spain, Canada, United States*).

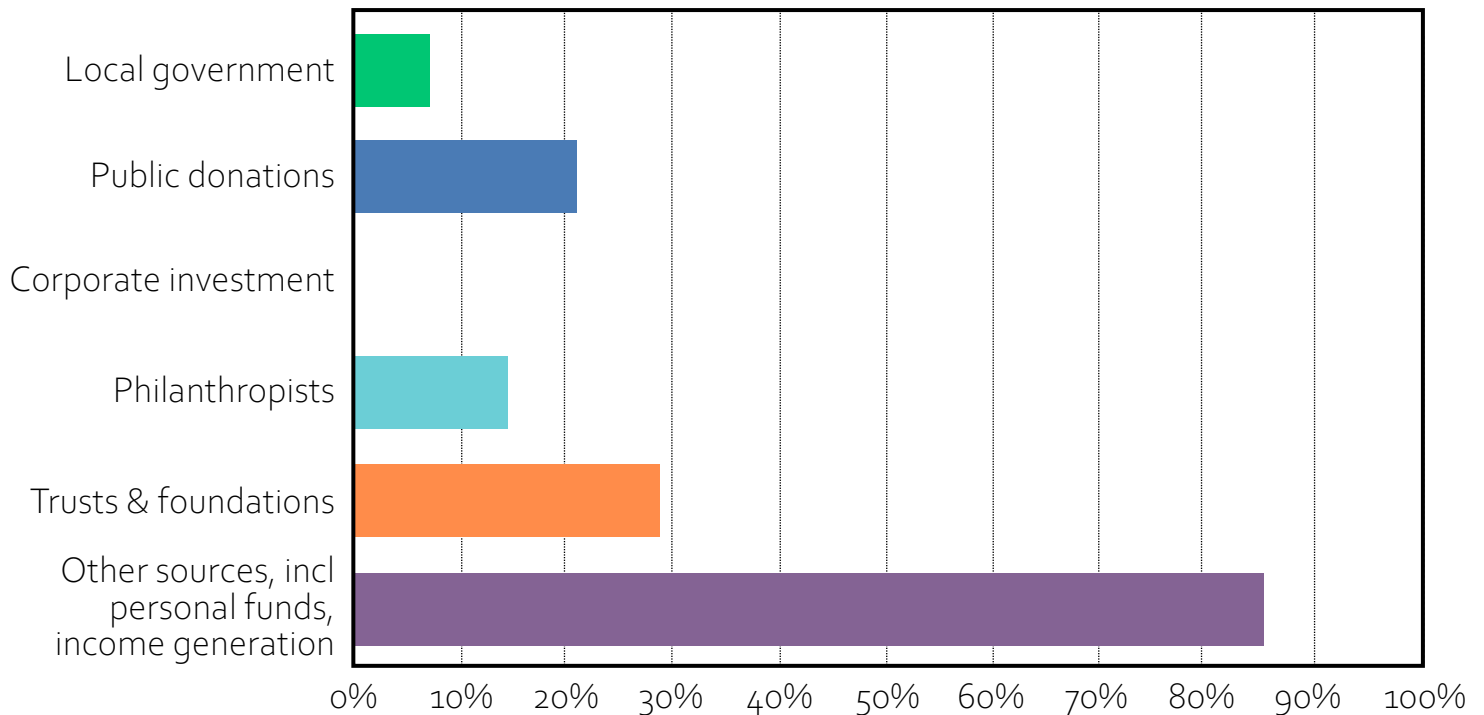
- **13%** of the organisations were international,
- **7%** regional and
- **80%** country level organisations.

FUNDING

The organisations reported that they had been funded through one or two sources, while most were not funded through conventional funding sources (*Figure 1*), but were able to survive (barely) through other sources, mainly using their own personal funds, with others noting income generation from services or being involved as collaborators in other larger organisational/ stakeholder projects.

Experiences of fellow peer-led organisations

FIGURE 1: FUNDING SOURCES TOWARDS LIVED EXPERIENCE/ PEER-LED ORGANISATIONS



The **16 (sixteen) organisations** submitted an overall average of 22 (twenty-two) applications in the past 2 years (2020-2022), with an average of 3 (three) of these applications received a positive outcome.

- **27%** organisations noted that they have received feedback from the funder/ donor, while **73%** noted that they have not received any feedback.
- **67%** organisations who received feedback, noted that they have received a generic response, while **33%** noted that they received feedback that were specific to their application.

Several organisations mentioned that they had applied for funding from funders/ donors who focus on social justice and human rights, however were dismissed with responses that they [the funder/ donor] do not fund mental health related initiatives and/or that mental health is not related to human rights or social justice. In contrast to these views, the primary existence of lived experience/ peer-led organisations is towards taking a stance on human rights and social justice.

Experiences of fellow peer-led organisations



ENGAGEMENT

- **13%** of organisations have **never received compensation/ payment** for consultative/ engagement work with other stakeholders, **60%** noted have only **sometimes received** remuneration, and **27%** noted **more often than not**.
- **80%** of participating organisations, felt that stakeholders **DO NOT value** lived experience perspectives and contributions to the mental health field.
- **93%** of participating organisations felt that, where people with lived experience are compensated for their intellectual and experiential contributions, such compensation was **NOT fair and equal** to that received by non-lived experience participants, while the remaining **7%** were unsure.

Experiences of fellow peer-led organisations

"Credibility since we don't have a track record of impact activities in the community, precisely because we haven't had funding." Lived Experience/ Peer-led Organisation, Cameroon

In order of most commonly mentioned reasons as the prime challenges that organisations have faced in securing funding:

- Lack of **capacity** and expertise to a) write competitive funding/ grant proposals/ applications and b) to develop fundraising strategies
- Insufficient length of **financial track** record/ years in existence
- Funders/ donors not providing financial support towards **operational expenses**
- Funders/ donors require **scientific impact** measures
- Important funders/ donors do not accept **unsolicited** proposals/ applications
- Funders/ donors are reluctant to invest in **smaller organisations**
- Academics and professionals **minimizing the value** of lived experience
- Unable to speak to a person to **enquire about funding/** grant opportunities and application guidance



"Communicating our vision into tangible outcomes that do not necessarily lead to traditional measures of outcomes. For example, a traditional metric of impact would be increased help-seeking, in particular clinical services. However, our work emphasises on the fact that our experiences and advice are just as important and that personal empowerment, agency are also important metrics." Lived Experience/ Peer-led Organisation, Singapore

Experiences of fellow peers

SURVEY 2: People with Lived Experience

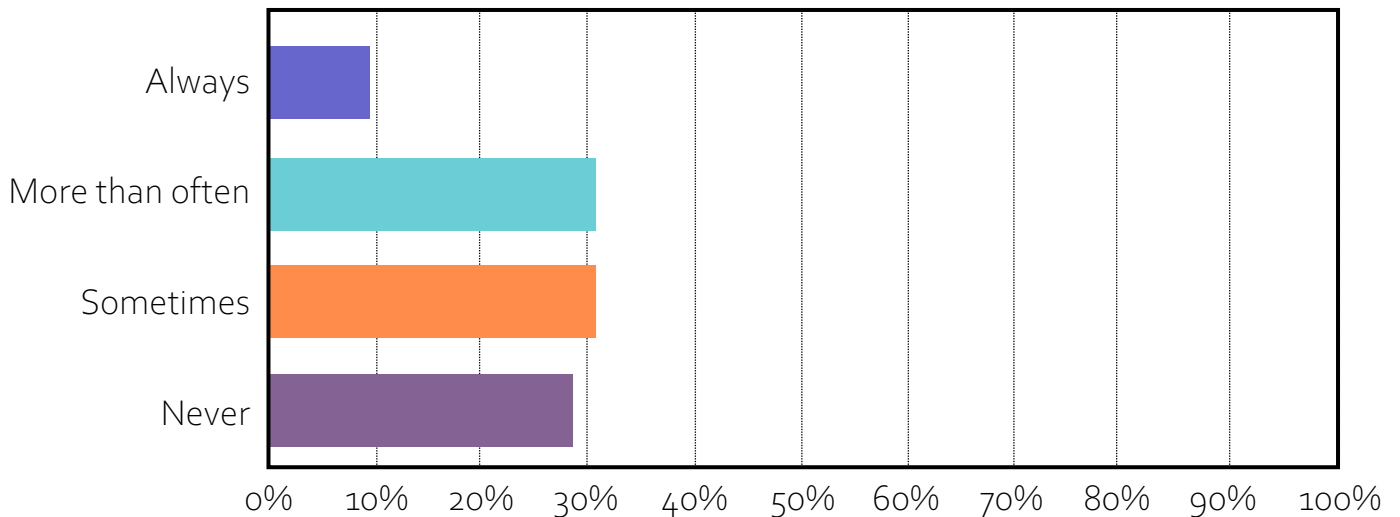
We developed an additional online survey, to specifically obtain experiences from individuals with lived experience who had been involved in engagement/ consultation work.

The survey link was shared within the GMHPN contacts and to and via partner organisations.

A total of **42 (forty-two) individuals with lived experience** participated in this exercise, from **across 23 (twenty-three) countries** (Botswana, Cameroon, Ethiopia, Kenya, Malawi, Nigeria, South Africa, Uganda, Zimbabwe, Zambia, Australia, Indonesia, New Zealand, China, Bangladesh, England, Ireland, Netherlands, Spain, Ukraine, Czech Republic, Canada, United States).

Participants in the survey noted that they had been involved in providing lived experience perspectives and contributions into a range of key documents and projects, and engaged at various discussion and decision-making platforms. These include: **policies and laws (43%), strategic plans (43%), toolkits and information materials (69%), research projects (69%), mental health service development (62%), community projects (48%), conference planning (62%),** amongst other activities.

FIGURE 2: FREQUENCY OF PAYMENT RECEIVED FOR ENGAGEMENT/ CONSULTATION WORK

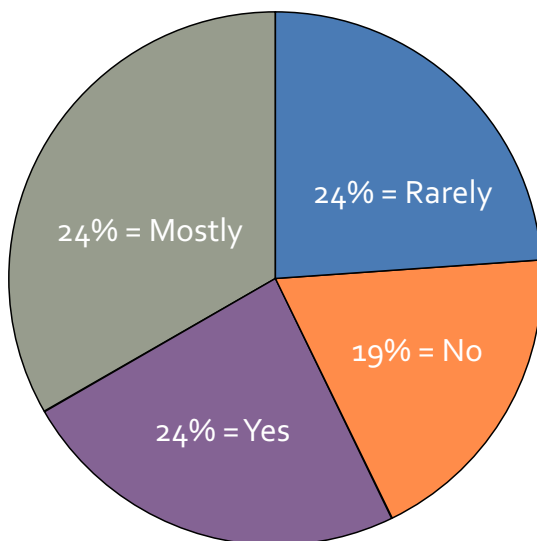


Across the various areas of engagement/ consultation work within which participants were involved (Figure 2), **less than 10%** of them noted that they **have always received remuneration** for their expertise. (Figure 2)

Experiences of fellow peers

Individual participants were asked to share whether they believe that stakeholders truly value lived experience perspectives and contributions to the mental health field – see *Figure 3*.

FIGURE 3: VALUE OF LIVED EXPERIENCE PERSPECTIVES AND CONTRIBUTIONS



It is worth noting that the survey results indicate that among individuals with lived experience (survey 2) there is a sense of feeling valued as opposed to **peer led organisations** (in survey 1) where **80%** of the participating organisations felt that lived experience perspectives/ contributions were not valued.

The results have noted that **22%** felt that compensation was fair and equal to that received by non-lived experience participants, while the remaining **52%** said no, and **26%** were unsure. Comparing these to the lived experience/ peer-led organisations responses (in Survey 1), **93%** of participating organisations felt that compensations was not fair and equal.

“Paid lived experience motivate[s] those participating to share their experiences. But non[-]payment demeans what they undergo making them feel demoralised.”

Experiences of fellow peers

"... Make a minimal income as a Mental Health Peer Specialist. +10 years' experience, a lifetime of lived experience, all training, internships, and accreditations done. However, I am rarely compensated for my 'expert' input, and design ideas. The odd research study will send a nominal gift voucher - an amount less than the minimum wage in Canada. Other experts are paid for their observations and experience. There has been an increased demand for this type of work - and we are expected to do it for free. I will never understand this. Money will not taint my perspective, or the voice I bring to my community. In fact, it may help me in earning a true living wage. Presently I am involved in 4 such projects. This takes about 20 hours a week. I am not compensated..."

All 42 (forty-two) participants indicated that they had been invited to present/ speak at conferences/ events and reflected on sponsorship received/ not received and what costs were covered by the inviters and of course the uncovered costs that they themselves were ultimately responsible for:

- **Time and expertise:** 50% were not paid; 26% partially paid; 21% fully paid
- **Data (virtual events):** 63% were not paid; 13% partially paid; 15% fully paid
- **Travel expenses (in person events):** 29% were not paid; 24% partially paid; 26% fully paid
- **Conference registration:** 33% were not paid; 14% partially paid; 33% fully paid

"For conferences or in-person events, visa fees are not covered, and it is often expected to cover own travel expenses and only later be reimbursed – not everyone has access to large amounts of money, especially if you are from a low- or middle-income country."

Experiences of fellow peers

"Paying to become a member or paying to register for an event that I'm speaking at, is not fair since I'm providing my lived experience to help the organisation who approached me, but I am still required to pay registration fees. In addition, I've had many instances wherein I was asked to attend conferences abroad but only to be told that the meal at the conference is covered but travel and accommodation is not paid for."



Conclusion

We recognise that the engagement surveys that we have conducted with lived experience/ peer-led organisations and individuals with lived experience was a small sample and that generalisation of experiences on a broader representative scale cannot be made. The data collected however, presented sufficient information to confirm that our own experiences are not unique. The lived experience/ peer-led organisations and individuals that we have engaged with, shared very similar barriers in securing funding and receiving compensation for engagement/ consultation, then we do. Challenges faced by organisations such as the GMHPN in securing funding support towards operational expenses, places lived experience/peer-led organisations at a disadvantage in so far as organisational sustainability is concerned.

It also hinders our work in placing lived experience voices central to shaping mental health care and programmes across the world into practices that address the real challenges and needs of people with mental health conditions at grassroots level.

"Those of us with lived and living experience shouldn't be expected to feel grateful to sit at the table, we should be paid to lead at the table... It's not good enough to have "token consumers" at the table to "tick the boxes" of being diverse and then not paying us properly or even at all, while the other experts around the table get paid. It is an entire skill set in itself to be able to talk openly about experiences that are often painful to think about or even traumatic, in a safe and effective way, and I don't think that's recognised enough. ... There needs to be more understanding and recognition about why it's essential to reimburse us properly for providing our diverse lived/living experiences, and the many valuable benefits, skills and areas of knowledge we bring to organisations and the decision-making process. ..."

The results of both surveys raise great concern about the limitations on the extent to which people with lived experience are valued for their expertise and contributions, and the impact upon their own empowerment and willingness to be open to stakeholder collaborations.

Discussion

We as experts (by experience) have unique and in-depth knowledge and understanding of the impact of mental health conditions and what is needed to remove the barriers to inclusion, equality and equity, stigma and discrimination free communities, sustainable development, and mental health for all. We are able to contribute in ways that no other expert in their field can offer.

We are uniquely positioned to provide cost-effective and practical solutions to promote and protect mental health among communities and advise decision-makers on how to strengthen and mainstream mental health interventions into various sectors.

Our contributions as experts by experience in our own right, have the potential to add immense value to (but not limited to) the mental health sector, with a potential long-term cost savings from services that will have improved outcomes and benefits to the service users, merely because such services or programmes are considered within the context of actual needs and challenges of target audiences.

Historically, we as people with lived experience have been excluded from opportunities to contribute our expertise and now that we are being included, we are considered as “volunteers” – receiving an honorarium at best. We would like to see a shift in the current mindset from viewing people with lived experience as merely volunteers to subject matter experts in our right and no less worthy than other experts.

By continuing to implement non-compensatory practices, our contributions remain devalued with emphasis being placed upon tokenistic approaches. To the contrary, remunerated engagement/consultation acknowledges the value and abilities of people with lived experience, and corrects power imbalances.

“ ... stakeholders say they appreciate the input of people with lived experience, but often 'forget' to really involve us and/or pay us.”

“I feel I have been so taken for granted and I just dropped one such engagement where I had been expressly told at the beginning last year there would be some compensation agreement, but nothing has been said since then.”

Recommendations

Recommendations for funders/ donors

1. Ahead of developing funding strategies, consult and involve people with lived experience from the planning stages to ensure financing goes to where it is needed most and can make the most impact
2. Align funding practices with international human rights instruments and strategies
3. Align funding strategies so as to not exclude population groups or current situations/ experiences that impact on mental health of all people
4. Funders to be clear on their strategies, expectations and limitations on the public information platforms (e.g. websites)
5. Reasons for rejected applications to be transparent, aligned with call for applications and not generic responses that prevent organisations from learning from the process

Recommendations for stakeholders

6. Adopt guidelines and policy to equal and fair practices when working and engaging with people with lived experience and their representative organisations
7. Anticipated lived experience inclusion should be adequately budgeted for in RFP's/ project proposals and so forth, ensuring alignment to fair practices and reasonable compensation for lived experience collaborators

Key Strategic Elements: Lived Experience Engagement

- ▶ Engagement must be included in the project strategy that provides for lived experience inclusion from the planning and conceptualisation of initiatives to the implementation, monitoring and evaluation phases.
- ▶ Planning must make provision for sufficient resources, logistical support and allocation of reasonable funds towards financial compensation for the lived experience representative/s and align with “equal pay for equal work”.
- ▶ Orientation and empowerment prior to project initiation to provide complete context and steps of the project, and clearly defined role/s, responsibilities and expectations of the lived experience representative/s.
- ▶ Reasonable accommodation measures to be available if needed and based on the individual needs as identified by them, and at all times ensure a safe space for engagement to enhance mental wellbeing.
- ▶ Be considerate of time frames in which engagements are planned - ensure sessions/ consultations are planned and scheduled in advance and within suitable times/ time zones, and ensure deadlines are reasonable.
- ▶ Prevent any power imbalances and risks of conflict by emphasizing equal stakeholder partnerships by adopting respectful and constructive conduct and applying principles that value: respect, responsibility, anti-discrimination, equality, confidentiality, honesty, integrity, trust, openness, fairness, transparency, anti-power imbalance.



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