

Valuing experts by experience

Zumbido Pulse
2022

Setting the scene

The Global Fund recently released their 5-year strategy announcing their intention to integrate mental health services into HIV and TB programmes in low and middle income countries¹. They have pledged \$18 billion to this task.

The growing body of research evidence is clear: addressing mental health in populations living with HIV and TB not only improves treatment adherence, and therefore health outcomes; it can also prevent future infections and accelerate progress towards reaching the Sustainable Development Goals and ending the AIDS, TB, and malaria as epidemics by 2030.²

This growing emphasis on integrating mental health and psychosocial support into HIV programmes is a hugely positive step. However, when systems of care are designed without listening to the people they are intended to support, they often fall short of their goals - or fail altogether.

In recent years, there has been growing recognition of the importance of listening to service users and people with lived experience, in both the fields of

HIV/AIDS and mental health, so as to design and deliver more effective systems of care.

But of course, good intentions aren't everything. Integrating mental health and psychosocial services into HIV programmes and drawing on the expertise of people with lived experience - or "experts by experience" - needs to be done in ways that **ensure their voices and perspectives are truly valued, meaningfully acted upon, and their well-being safeguarded.**

Otherwise, it can risk being done in ways that are either tokenistic or triggering for those experts by experience.


In this edition of Zumbido Pulse we share our experience of running mental health and psychosocial support groups for young people living with HIV and our approach to involving people with lived experience in the design, implementation and adaptation of those programmes. We share what we've learned from these processes, and the impact it has had on our participants and their mental health.

1. The Global Fund (2022) Fighting Pandemics and Building a Healthier and More Equitable World : Global Fund Strategy 2023-2028. Access online here.

2. Remien; Stirratt; Nguyen; Robbins; Pala; Mellins (2019) Mental health and HIV/AIDS: the need for an integrated response. AIDS. doi: 10.1097/QAD.0000000000002227

A reminder

The Zumbido Health Model



The Zumbido Health Model uses mobile phones to create mental health and psychosocial support groups for vulnerable, socially isolated groups of people, particularly those living with stigmatised health conditions such as HIV.

Enabled by a digital platform, participants in the groups discuss - peer to peer, at any time, via text message - a range of topics pertinent to their condition or needs.

Zumbido aims to create spaces for people living with stigmatised health conditions where they not only access support and feel less alone, but where they can also offer support to others experiencing similar situations.

The Khuluma Experts by Experience

In South Africa, the Zumbido programme is called Khuluma, and the participants are young people living with HIV in Pretoria. Khuluma has now been running for 9 years, and the Khuluma Experts programme has developed alongside it: a 'train the trainer' model in which some participants go on to become supporters for other HIV-positive young people.



The Khuluma Experts receive financial support, food packages, mental health care, technical qualifications and skill-building to build their employability and support their overall wellbeing.

The Khuluma Experts now support in the running of all Khuluma groups, and in replicating the Zumbido model in other parts of Southern Africa. They also support participatory research projects with our academic partners.




The Zumbido approach to working with experts by experience

Before getting into the details of which processes and activities we involve people with lived experience in, let's go through how we approach that involvement:

We care for experts by experience as complex and multifaceted people. We are holistic - caring for social, emotional, physical and mental wellbeing, and not only thinking of them as individuals but as members of their communities

We build long-term relationships and provide tailored support - we get to know everything about each of the mentors, about their lives, backgrounds and dreams

We listen to young people's perspectives and voices and use their insights to effect positive change in the system




We envision and build towards their future beyond the programme, rather than keeping young people forever stuck as 'mentors'

We also care about their physical wellbeing, providing them with care packages to support basic needs

Practical examples

Involving experts by experience in
the design and implementation of
the Zvandiri Lounge



The SHM Foundation partnered with Zvandiri, a community-based organisation in Zimbabwe, that seeks to ensure healthy, happy and fulfilled lives for young people living with HIV.

Zvandiri do this through a peer-to-peer system in which adolescents living with HIV - called Community Adolescent Treatment Supporters, or “CATS” - are trained and mentored to provide prevention, treatment, care and support services to their peers.

Already integrated within national health services, Zvandiri’s programme had begun to be replicated in other countries.

Their challenge was, as the model expanded, how could they ensure that the CATS themselves have the support that they need?

We partnered with Zvandiri on a collaborative project, funded by ViiV Healthcare, to design a support system for the CATS.



Co-design

Involving experts by experience in designing the intervention

Through a 10-day “immersion experience”, we spent time engaging with a group of 19 CATS through workshops, home visits and visits to clinics, so as to draw out their experiences, perspectives and priorities and put their voices at the centre of the intervention design.

Khuluma Experts were engaged in facilitating the workshops, using creative, dramatic and artistic methods to understand what existing support structures the CATS had, and what their fears and challenges were in their daily life.

Khuluma Experts worked with the CATS to build prototypes of support systems that were then integrated into a single solution.

Through this process, an ideal support system emerged, with two distinct parts:

A ‘lounge’

where the CATS could access peer and professional support informally anytime, anywhere

A ‘tool shed’

that equipped them with the resources, knowledge and guidance they needed

Implementation

Tech support, monitoring and facilitation of digital support groups

The 'Lounge' that we developed was an adapted version of the Zumbido model (you can read more about its specifics in 2021's Zumbido Pulse). The participants could communicate at any time, anywhere about the issues pertinent to their needs via the digital Zvandiri Lounge.

The groups were co-facilitated by a representative of the SHM Foundation team, a Khuluma mentor in South Africa and a CATS worker who had been given basic mentor training.

Putting service users of the Zumbido model in the driving seat to contribute to how the groups were facilitated helped to create a truly peer-to-peer environment where CATS were able to relax and be themselves.

Khuluma Experts were also involved in monitoring the group conversations for safeguarding purposes.

The groups were critical pathways for referral of adolescents who needed more acute care from the psychologist or to their district mentor.

Replication and scale-up

Peer-to-peer training in peer-to-peer support

The success of the CATS Lounge led to the SHM Foundation and Zvandiri collaborating on a further project to replicate and expand the model as a support system for Young Mentor Mothers (YMMs) - young mothers living with HIV who provide psychosocial support to peers.

When it came to training YMMs to go on and run digital support groups for other young people, it was clear the Khuluma Experts would be perfect to build their skills.

Two of the Khuluma Experts paid a trip from South Africa to Zimbabwe to run a series of training workshops with a group of YMMs, to train them in digital facilitation and how to run the tech platform.

"Having been a participant of these groups in the past years, and gone on to help run them, I have learned a lot when it comes to facilitation. So I use all that I have learned to teach the new facilitators and share the skills which will make their work easier. The skill of keeping participants excited and present, introducing new topics of conversation, including some that are tricky or complex, and what the role of the facilitator is in these spaces."

Desmond, Khuluma Expert

"Being a mentor and facilitator of Khuluma groups has given us the skills and knowledge to deliver this training. I feel this process has sharpened my skills in presenting information and training others - skills I hope to put to use lots in future."

Kelebogile, Khuluma Expert



Evaluation

Involving service users and experts by experience in evaluation and analysis

Khuluma Experts also play an important part in the impact and evaluation stage of Zumbido projects.

The evaluation of the latest Khuluma support groups was almost entirely managed by the Khuluma Experts.

They worked closely with our team to firstly review and adapt the content of the pre and post evaluation questionnaires, and then carried out interviews with participants. They also carried out the analysis of the text messages sent and received in the Khuluma groups, and, through a number of workshops, worked with our team to identify key themes and insights that came out from the conversations in the groups.



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The ripple effect

How does...

engaging with experts by experience lead to better systems of care?

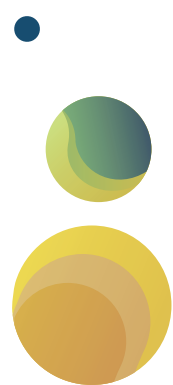
Organisations that engage meaningfully with experts by experience and/or service users are better equipped to create truly effective and impactful services.



How does...

this process impact the lives of the Khuluma Experts?

The impact of being involved as an expert by experience in meaningful ways, and truly valued for your perspective, can be felt on both individual and collective levels:



Individual

Building skills, knowledge and expertise

Generating empathy and understanding through exchange of perspectives

Cultivating inner confidence and agency

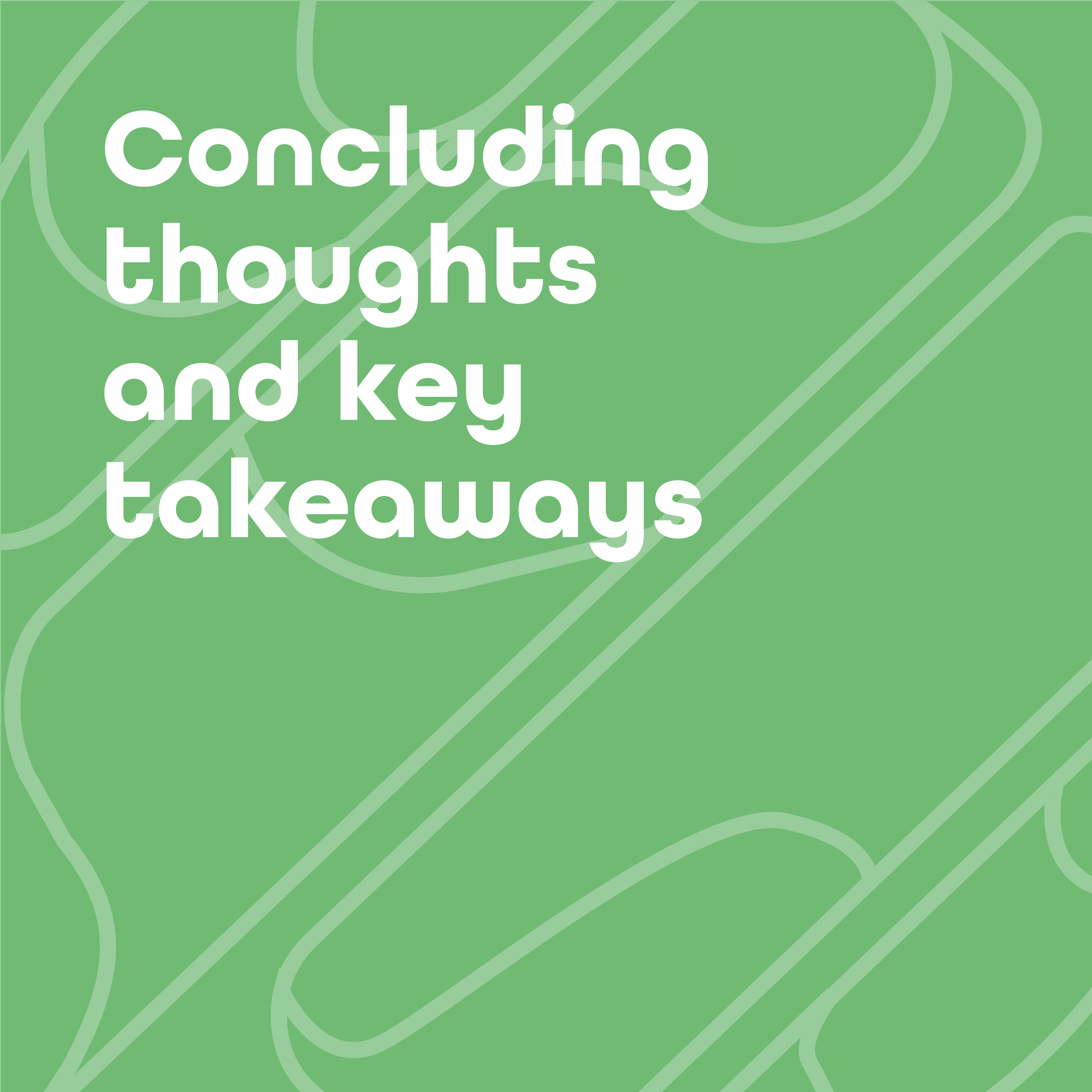


Collective


Creating ways for young people living with HIV to be agents of social change in systems that affect them

Fostering a community of empathy, activism and inspiration

Building recognition for the valuable contributions and expertise of this community

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**Concluding
thoughts
and key
takeaways**



Integrating mental health and psychosocial services into HIV programmes and other areas of health has hugely positive impacts on health outcomes.

It is fantastic to see the growing recognition - in HIV/AIDS care and beyond - of the importance of mental health alongside physical health.

However, in integrating mental health into other systems and services, it's important to incorporate the voices of service users and people with lived experience of HIV/AIDS.

This is not a tick-box exercise.

As implementers, funders, researchers and other types of stakeholder, we should be creating the right conditions for experts by experience to make meaningful contributions that shape decision-making about the services that affect them.

After more than a decade of running Zumbido programmes, here are our top tips about how to create those conditions:

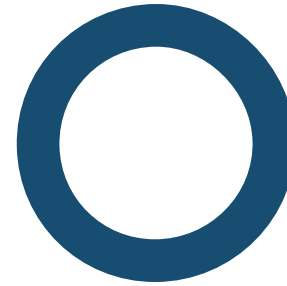
Incorporate the views and expertise of people with lived experience at all stages of a programme's life cycle - from intervention planning and design to evaluation - not just as a kick-off or bolt-on activity.

Use a variety of methodologies for getting input from people with lived experience - and try to make it an enjoyable experience.

Consider what will suit the population and context you're working with and what will create a safe, supportive and open environment.

Bring relevant experts by experience into your team and nurture their skills.

Offer them support that they need to be able to dedicate their time and contribute to programmes.



Experiment to find what works.

Ask what they need and, wherever possible, consider financial compensation for their participation.

Create a safe and supportive environment, and make sure you're not being extractive.



Be mindful of possible traumas they may have been through and choose a careful and considerate approach.

Be sensitive to the fact that everyone has complex and multifaceted lives. Everyone has pressures on their time, stresses they're facing, and they won't be confined to one particular area.

Take these considerations into account in planning how to engage people with lived experience



We would encourage all organisations funding, designing and implementing programmes, or conducting research projects, to consider how they can meaningfully engage experts by experience in these processes



We should always be questioning how we can ensure the processes for doing so lead to meaningful, valuable and caring exchanges of insight, and contribute to better overall systems of care

Thanks for reading! Please get in touch with any questions or comments, or if you're interested in collaborating with the SHM Foundation on a project.

You can look back at previous editions of Zumbido Pulse to understand the more about our approach to co-designing social support interventions in partnership with experts by experience.

You can find the [2020 edition here](#) and the [2022 edition here](#).