WE NEED A MENTAL HEALTH MOVEMENT LED BY PEOPLE WITH LIVED EXPERIENCES

A few years ago, when my colleagues and I organised the first mental health advocacy walk in Durban, the public spirit was infused with excitement and possibility from get-go. We started with a few dozen people at our first walk in 2016 and this grew to over 1000 by 2019. There was a genuine desire from citizens to show up and speak up.

I was not surprised by the positive uptake. Results from the Global Burden of Disease Study (1990-2017) show that mental disorders are in the top 5 leading causes of disability in sub-Saharan Africa and that depression was on its way to become the leading cause of disability by 2030. Yet, the treatment gap in South Africa is over 90% with appallingly low public spending on community mental health. In fact, I was shocked that the hundreds of patients languishing on long waiting lists at most hospitals were not already taking to the streets to demand that government employ more healthcare workers.

However, despite the obvious need for radical activism, the transformation of this need into a citizen-led movement has been slow. As professionals, we used our convening power to create the advocacy walk, but hoped that patients, or service-users/people in recovery, their families, communities, allies and fellow activists would leverage the initial successes and take ownership of its future direction. A thousand people pitching up once a year to destigmatise mental illness is amazing; but how do we keep mental health activism on the agenda for the other 364 days of the year? In light of the emotional earthquake caused by Covid-19, isn't it obvious – yet! – that mental health really does matter?

For complex reasons, it's difficult for ordinary citizens to drive advocacy. Foremost, the healthcare system is not enabling of, and receptive to, the voices of the people it's meant to serve. There are structural barriers preventing people's voice taking center stage. Speaking up is one thing; being heard is another.

Redefining 'experts'

There are few, if any, embedded spaces in the healthcare system that actively solicit and implement the advice of people living with mental illness. For example, how does it feel to undergo a 72-hour observation, as per the Mental Health Care Act? Do people with suicidal thoughts know where to access help? When people are put on waiting lists to see a psychologist or psychiatrist, what do they do in the meantime? Why is adherence to psychotropic medication so difficult for some people? Do people feel empowered to tell their GPs about mental distress? Do GPs routinely screen for depression, self-harm, substance abuse, or neuropsychological decline, given that GPs are the first point of contact?

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These questions speak directly to the daily realities of people who navigate a complex and often confusing health "care" system. For service-users who feel disempowered, turning to advocacy is not easy. Even laying a straightforward complaint about bad service requires inordinate courage that few are willing to muster up. The tired refrain from public sector managers that "we are under-resourced and over-worked" is often used as an excuse to dismiss patients' experiences; yet, service-users may have ideas to improve the system but remain an untapped resource.

Nothing about us, without us

Optimistically, global mental health advocacy efforts are waking up to this important issue and breathing new life into the slogan 'nothing about us, without us.' For example, the Global Mental Health Peer Network (GMHPN) are "unapologetically experts by experience" whose objective is to create communities where persons with lived experience are valued "as equal citizens of the world, free from stigma, discrimination, inequality and inequity". The GMHPN has six South African representatives who are active advocates at a global and regional level.

The CEO of GMHPN, Charlene Sunkel, has been at the forefront of this work and shared some insights with me. "With people with lived experience being meaningfully and authentically included in co-creation and decision-making processes, mental health systems have a far better chance of providing services that are addressing the actual needs and challenges of people with mental health conditions and delivering services that can allow people to thrive and not just survive," says Sunkel. South Africa, however, is lagging behind.

"As far as my knowledge goes, there are no strong, united and independent lived experience group in South Africa who are actively advocating for what they feel is important," says Sunkel. "Some of the groups that do exist function under the direction of NGOs, thus lacking autonomy. There are stumbling blocks that hinder the establishment of independent and united advocacy group/s in South Africa, ranging from lack of financial investment and prioritisation to support the development and management of local lived experience groups. Other factors range from stigma and discrimination, lack of empowerment of mental health care users, cultural and language barriers, low education levels, to poverty".

Indeed, the GMHPN Charter makes the important point that "The mental health system is not the only societal system that poses obstacles to navigate through – for a person with lived experience, accessing other life opportunities such as education, employment and housing are equally difficult." This reorientates mental health as intersecting with the material conditions that often give rise to psychosocial distress.

Chantelle Booysen, a project manager at SADAG's KZN office in Durban, has used her own history with bipolar mood disorder to speak up. She agrees with Sunkel. "There are multiple reasons why lived experience leadership in this country falls short. It's not always given the respect that it's due," says Booysen. She believes that we lack a relatable advocacy platform where people from all walks of life and varied experiences of mental illness can sit around a table and talk. "There is little political will to provide this platform. Advocacy is successful when there is a clear connection with a political outcome, whether its local government or municipal level."

There have been some special projects that pop up, for example, by the South African Federation for Mental Health, or the Presidential Committee on Mental Health, but the problem appears to be sustainability and impact. Booysen warns that initiatives must go beyond "paper-pushing exercises" that tick the boxes for inclusion, but don't result in tangible outcomes that improve service delivery experiences on the ground, and quality access to mental health.

Towards a united voice

Over a decade ago, Professor Jonathan Burns asked a pertinent question in an editorial for the South African Medical Journal: "What can advocates of mental health service transformation learn from the extraordinary success of the HIV/AIDS advocacy movement?" This question still has relevance. The Treatment Action Campaign is one of our best examples of citizen-led advocacy that resulted in tangible change in national government policy, subsequently saving hundreds of thousands of lives by improving access to ARVs.

A culture of protest is part of our national identity. We are described as the protest capital of the world when it comes to service delivery issues; however, those issues go hand-in-hand with mental health and cannot be separately fought for. Not having water or electricity causes emotional distress; using a pit latrine in school affects educational outcomes.

I am reminded of a memorable placard that a young woman was carrying at our last in-person advocacy walk. It read, "Your feelings ARE valid!" Indeed, this is perhaps at the heart of the current matter. To create the conditions for a viable mental health advocacy movement in South Africa, we need to begin with the foundational assumption that the lived experiences of mental healthcare service users are valid, important, and necessary to radically transform the current status quo. As professionals, we must support this movement, or at least move out of the way and clear the path for those who want to be heard.

Wellcome Trust, a global charitable foundation that funds health research and advocacy initiatives, routinely pays lived experience experts as "advisors" on their mental health projects. They ran a webinar last year in which Booysen participated, about putting lived experience at the heart of mental health policy and practice. Will this message be heard loud and clear?

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