

# Lived experience: shifting focus

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**The language of mental health is always being updated to better capture states of being and to be more inclusive. ‘Lived experience’, the core qualia of a mental health condition as it is perceived and inhabited by an individual, reflects this evolution. It is what makes some of us mental health ‘experts by experience’.**



**P**arsing the mental health lexicon means recognizing where more work may need to be done, how priorities have been shaped and how individuals are considered within specific frameworks, such as health systems or the broader workforce. The incorporation of the term ‘people with lived experience’ (PWLE) or referring more broadly to lived experience and mental health has, over the years, taken on the status of a movement. Much of that movement has revolved around changing attitudes or perceptions about PWLE of mental illness and breaking down stigma, but it has also provided meaningful shifts in public discourse and major legislation and international treaties, such as the historic [National Mental Health Act](#) of 1946 that established the National Institutes of Mental Health, the [Americans with Disabilities Act \(ADA\)](#) in 1990 and the [United Nations Convention on the Rights of Persons with Disabilities](#) in 2006, to safeguard the civil and human rights of people with disabilities.

The lived experience movement has been shaped and spurred on by the wider Disability Rights Movement, out of which the motto “Nothing About Us Without Us” emerged. It is a philosophy that aims to challenge oppression of and discrimination against people with disabilities who have often been marginalized or excluded from economic and social opportunities and to demand representation and involvement in policy-making that affects specific individuals.

From the perspective of mental health, a “Nothing About Us Without Us” approach

equates to a wide set of ways to involve PWLE of a mental health diagnosis or condition. The keystone of mental health research is the individuals who participate in a study or a clinical trial, who share their lived experience with clinicians and researchers, in order to advance our understanding and with the highest goals of alleviating suffering and improving lives. Yet throughout the mental health research enterprise, there are opportunities and space where PWLE can bring transformative insight and guidance. Again, the labels of these positions matter within mental health research and advocacy work. Terms such as consumers, survivors, service users, embedded researchers, peer support workers, carers and public service crises responders speak to the breadth of roles and capacities that individuals may fulfill.

In this issue of *Nature Mental Health*, we are pleased to share our first steps as a journal in underscoring the many ways in which PWLE contribute to and enhance mental health research. In a [Correspondence](#) from Sarah Chellappa at the University of Cologne, Germany, we are urged to consider how ableist language prevents neuroinclusivity, and the value of incorporating the neurodiverse community in participatory research and coproduction of scholarly work. We also spoke with Thema S. Bryant, President of the American

Psychological Association, in a [Q&A](#) about her expertise and advocacy and the lived experience of the trauma of racism and the effect on the mental health of Black people.

We present pieces on the participation of PWLE in mental health research from three different vantage points – from experts themselves, within a national translational research center, and from mental health research funders. Grace Gatera and Shuranjeet Singh, from the Wellcome Trust Lived Experience Consultants, offer [commentary](#) on the functions of Wellcome Trust Lived Experience experts and the emphasis on increasing equity through global representation and actively reducing barriers for PWLE experts through ongoing training and capacity building. A [Comment](#) from Andreas Meyer-Lindenberg details the organization of the newly created German Center of Mental Health and the Patient and Public Involvement infrastructure designed to include children, adolescents and adult service users at each stage of the research process. From the perspective of mental health research funders, we include a [Comment](#) by Raliza Stoyanova, Rory White and colleagues that summarizes the findings of a survey that was conducted by the International Alliance of Mental Health Research Funders, which demonstrates recent shifts toward increasing the incorporation and participation of PWLE in funded mental health research, but that urges the need for unified strategies and best practices across funders for meaningful and productive lived experience involvement.

It must be said that as a new journal, we are only just learning how to navigate the spaces in mental health that we feel strongly should be explored, highlighted and consulted. In the coming months, we will bring other perspectives from PWLE, including publishing insightful interviews, narratives of lived experience in academia and other workplaces and primary research. We hope to hear from our readers – mental health experts of all kinds – about where we set our sights next.

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