

Lived Experience, Research Leadership, and the Transformation of Mental Health Services: Building a Researcher Pipeline

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In recent years, investment in participatory research methods within mental health services research has grown. Participatory efforts are often limited in scope, however, and attention to research leadership is largely absent from discourse about stakeholder involvement in the United States. This Open Forum calls for investment in building a pipeline of researchers with significant psychiatric disabilities and intersecting lived

experiences frequently studied in public sector services research, including homelessness, incarceration, comorbid health problems, structural racism, and poverty. A series of concrete steps are described that faculty and research leadership can take now.

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Over the past 20 years, participatory approaches to mental health services research have gained considerable momentum and growing representation within the pages of *Psychiatric Services*. However, as both reviews and national surveys suggest, participatory involvement efforts tend to be mostly surface level, often limited to a stakeholder advisory group or to “one-touch” consultation activities (1–3). Although coproduction, in which researchers and community members exercise equivalent leadership, are important additions to the family of meaningful involvement strategies, concerns have consistently been raised as to the extent to which such approaches actualize stated goals. Furthermore, significant structural barriers, such as the ineligibility of nonfaculty researchers for National Institutes of Health primary investigator roles, fundamentally limit and reproduce inequities in capacity to initiate and lead funded research.

We therefore argue that in order to play a more meaningful role in research and, in turn, realize the potential for deeper and more transformative change, individuals with lived experience of the conditions, systems, and services we study must be central research decision makers (4–6). Consultation—understood as predominantly unidirectional activities designed to gather stakeholder input or feedback—is not a substitute for direct involvement and leadership of persons with lived experience in project decision making (4). In research contexts, this means major roles in developing research ideas, setting agendas, and obtaining funding for substantial research projects and in initiating and leading such projects. Reaching this level of involvement of individuals with

lived experience will require a serious investment by the mental health services research community in developing and sustaining a pipeline of mental health services researchers with experience of significant disabilities.

What “Lived Experience” Means Here

Before we continue, a note about terminology. Whenever advocates make the argument for greater involvement of people with lived experience in the research process, a frequent counterargument is that people with mental illness are already amply represented within existing research efforts: among students, faculty, and clinicians. If our definition of lived experience is mild to moderate anxiety and depression, such as are treated in an outpatient or primary care setting, this is demonstrably true (7). In fact, the myriad social and academic pressures within research pathways have themselves been repeatedly associated with high stress and poor mental health.

In this Open Forum, our purpose is not to define lived experience or its variants in any particular way but rather to pivot in order to emphasize diversification of the perspectives represented, with explicit attention to severity of impact and intersectionality. Clearly, there is a continuum from mental health to (functional) disability, and from widely accepted (normative) psychological and emotional states to those socially constructed as nonconsensual and unacceptable. In this Open Forum, we want to emphasize the need for greater inclusion of individuals at the farther end of these continua: those with the most (potentially) disabling and

stigmatized diagnoses, such as schizophrenia, borderline personality disorder, and severe substance use disorders; with intersecting experiences of the public benefits system, homelessness, housing instability, incarceration, poverty, racism, and other forms of structural discrimination; and whose experiences or diagnoses, for one reason or another, have led to strongly negative societal responses, including social rejection and clinical force. Too often, debates about the terms we use (“lived experience,” “service user,” etc.) serve to obscure a continuing reluctance to commit to, and support, individuals who have faced significant and substantial barriers to their participation in higher education and research, thereby also excluding the insights and experiential knowledge that such histories help engender. Through the remainder of this Open Forum, we use the abbreviation PD/LE (for psychiatric disability/lived experience) to refer to significant psychiatric disabilities and lived experiences.

Blueprint for a Transformed Workforce

With this context in mind, the particular goal of this Open Forum is to advocate for intentional and formalized workforce development. Specifically, we call for efforts and initiatives that acknowledge and support people with PD/LE across the academic training and funding continuum—including undergraduate students, research assistants and associates, and early- and midcareer researchers—and that do so on a meaningful scale. Rather than supporting or celebrating a small handful of researchers who have made it “against all the odds,” we ask for investment in building a sustainable pipeline of diverse PD/LE mental health services researchers and making systemic changes to help ensure that significant psychiatric disabilities are ultimately significantly better represented within the ranks of tenured faculty and extramurally supported primary investigators.

Expanding on broader research and best practices in mentoring, workforce diversity, inclusion, and antidiscrimination (8), we propose a series of actionable steps. (A table detailing these steps is available as an online supplement to this Open Forum.) These steps are meant to be suggestive rather than comprehensive, and they exclude broader supports with relatively more established empirical and political backing (such as student and employee wellness programs).

Proactive Recruitment, Hiring, and Sponsorship

As has been the case with efforts to diversify the research workforce in terms of race and gender, recruitment and hiring of students, staff, and researchers with PD/LE must be proactive. Academic programs and research teams should, for example, reach out to peer or service user groups and organizations on campus and in the broader community. Recruitment advertisements must convey thoughtful, concrete support for PD/LE and explicitly encourage applications from individuals with experience relevant to the focus area of the lab or research center. For example, a center focused on homelessness and mental illness might communicate a strong

interest in applicants with a history of homelessness or mental health challenges. We want to emphasize that with a newly funded project, there is almost always a choice between hiring one or more students or support staff identified with the community of interest and prioritizing efficiency, as the rationale sometimes goes. We strongly encourage investment in the former. Disability statements as part of the application process are a legally sanctioned way of discerning what a given applicant might bring to the table, especially when support for PD/LE has been successfully communicated.

Combating Academic Ableism

Work environments must be welcoming to newly recruited students and staff with PD/LE and offer them specific supports as needed. Critically, this must include a flexible approach to work and academic accommodations and an active commitment to challenging ableism—that is, the assumption that psychiatric disability, particularly when involving psychosis or cognitive challenges—is the antithesis of academic excellence (9). All too often, students and young people with a history of significant disability will already have internalized society’s judgments and lowered expectations of them. Patience, flexibility, and reassurance from senior faculty, mentors, and supervisors are essential. Additional direct and indirect actions (see the online supplement) include increasing the visibility and representation of researchers with disclosed PD/LE on journal and professional association boards and committees and as expert commissioners and invited speakers at conferences and colloquia. They should also include working to develop academic cultures that emphasize the value of the perspectives and insights that those with PD/LE bring. Rather than holding value as “token” representatives, these researchers’ perspectives should be embraced inasmuch as they inspire teams to ask different research questions or pursue different kinds of goals.

Recognition of and Support for Multiple Roles and Identities

Students, fellows, and research staff with PD/LE identities often face a unique set of emotional challenges navigating research spaces in which it is normative to speak of individuals with mental health or psychiatric diagnoses in othering, medicalized ways. A dispassionate discussion of outcomes tied to involuntary hospitalization or restraint that is unremarkable to a student with no connection to such experiences, for example, can be deeply painful for students who have themselves been restrained in an inpatient ward. Typically, such pain is suppressed in order to appear as an objective scientist. Similarly, research trainees may be asked to adopt language (e.g., “mental illness” or “brain disorder”) that has been rejected by the advocacy community with which they identify. These situations can easily become a major source of personal stress for individuals, particularly early in a research career when it is difficult to speak up and request changes to collaborative work or feel sufficiently

empowered to communicate the concerns of a particular community. Over time, internal struggles can further erode students' confidence. Having a mentor who validates these struggles, and personally addresses them where possible, is critical.

Breaking Glass Ceilings

In the United States, individuals with disabilities of all kinds remain seriously underrepresented among the ranks of tenured faculty (9). As has been well documented with respect to women and members of underrepresented minority groups, mentoring and support cannot stop with the completion of a doctorate. Both tenure and "independence" in research funding are glass ceilings that can be exceptionally difficult to break through. To assist in doing so, mentors, department chairs, and others in leadership positions need to commit to actively supporting the retention, promotion, and successful grantsmanship of fellows and junior faculty with PD/LE. Many models to support advancement for other underrepresented groups have been developed, including targeted fellowships, mentoring programs, and summer training institutes (8). To the best of our knowledge, no such explicit structures exist for researchers with PD/LE in psychiatry and allied fields.

Speaking Up and Speaking Out

We are aware of at least a handful of researchers who have written "coming out" stories, some within the pages of *Psychiatric Services*. Important, if not exceptional, efforts to address discrimination in licensure have been led by senior clinicians with lived experiences (10), as have been efforts to document the disclosure and accommodation experiences of faculty with psychiatric disabilities (11). There are nevertheless innumerable times and places in which speaking out on issues of inclusion would be possible, many with existing analogs to efforts to address the lack of inclusion of women and racial-ethnic minority groups: for example, board members—whether of a journal or research association—could call attention to the lack of PD/LE representation, or faculty could actively question admissions practices in which disclosure of mental health experiences are flagged as a "kiss of death," as has been reported in the literature (12). Speaking out is important both locally and in public venues such as academic journals. For example, the impact of senior thought leaders publicly pushing for greater support and inclusion of those with PD/LE in academic projects could be far reaching.

Conclusions

In this Open Forum, we have argued that the actualization of meaningful involvement of individuals with PD/LE in research requires not just inclusion but leadership. We call for greater, and more purposeful, investment in building a pipeline of researchers with personal experiences of

significant psychiatric disabilities or with other frequently studied target experiences in mental health services research in the public sector. Investing in this pipeline will require commitment and action—commitment that remains achievable and fully aligned with the social justice aspirations of fields such as community psychiatry, community psychology, and social work. We encourage leaders in these fields to embrace this challenge and to act now.

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