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

Nev Jones[1*], Kendall Atterbury[2], Louise Byrne[2,3], Michelle Carras[4], Marie Hansen[5] & Peter Phalen[6,7]

1. Department of Psychiatry & Behavioral Neurosciences, Morsani College of Medicine, University of South Florida, Tampa; **Corresponding author:** Nev Jones genevra@usf.edu

2. Program for Recovery and Community Health, Department of Psychiatry, Yale University, New Haven

3. School of Management, RMIT University, Melbourne, AU

4. Department of International Health, Bloomberg School of Public Health, Johns Hopkins University, Baltimore

5. Department of Psychiatry, Columbia University Vagelos College of Physicians and Surgeons, New York, NY, United States

6. VA Capitol Healthcare Network (VISN 5), Mental Illness Research, Education, and Clinical Center (MIRECC), Baltimore

7. Division of Psychiatry, University of Maryland School of Medicine, Baltimore

Abstract

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 in the United States. In this commentary, we call 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, co-morbid physical health problems, structural racism, and poverty. We describe a series of concrete steps that faculty and research leadership can take now.

Over the past 20 or so 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 "one touch" consultation activities.[1-3] And while co-production strategies, in which researchers and community members exercise equivalent leadership are important additions to the family of meaningful involvement, concerns have consistently been raised as to the extent to which such approaches actualize stated goals; further, huge structural barriers, such as the ineligibility of non-faculty researchers for NIH primary investigator roles, fundamentally limit, and reproduce inequities, in capacity to initiate and lead funded research.

In order to play a more meaningful role in research and in turn realize the potential for deeper and more transformative change, we thus argue that 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 in

project decision-making.[4] In research contexts, this means major roles in developing research

ideas, setting agendas, obtaining funding for, initiating and leading substantial research projects.

Reaching this level of involvement, in turn, 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 "mental illness" is 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 that 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 pivot 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 non-consensual and unacceptable. In this paper,

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

employ ("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 paper

we use the abbreviation PD/LE to refer to significant psychiatric disabilities/lived experience(s).

Blueprint for a transformed workforce

With this context in mind, the particular goal of this Open Forum is to advocate for intentional,

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/associates, and early- and mid-

career 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 diverse and sustainable pipeline, and making systemic changes needed to help ensure

that PD/LE researchers 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 detailed in Table 1. These steps

are meant to be suggestive rather than comprehensive, and exclude broader supports with

relatively more established empirical and pollical 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 PD/LE students, staff and researchers must be proactive. Academic

programs and research teams should, for example, reach out to peer/service user groups and

organizations on campus and in the broader community. Recruitment advertisements must

convey thoughtful, concrete support forPD/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 strong interest in

applicants with a history of homelessness and/or mental health challenges. We want to

emphasize that there is virtually always the choice, with a new funded project, to hire one or

more students or support staff identified with the community of interest or instead, as the

rationale sometimes goes, to prioritize efficiency; 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.

Combatting academic ableism

Work environments must actualize the support conveyed in welcoming recruitment materials.

Critically, this must include a flexible approach to work and academic accommodations, and

active commitment to challenging ableism—i.e. the assumption that psychiatric disability 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. Patience, flexibility and reassurance from senior faculty, mentors and supervisors

is essential. Additional direct and indirect actions noted in Table 1 including increasing the

visibility and representation of disclosed PD/LE researchers on journal and professional

association boards and committees, and as invited conference and colloquia speakers, and

working to develop academic cultures that emphasize the value of the perspectives and insights

that PD/LEs bring.

Recognition of and support for multiple roles and identities

Students, fellows and research staff with "lived experience" identities also often face a unique set

of emotional challenges navigating research spaces in which it is normative to speak of

individuals with mental health/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 a student who has themselves been restrained in an inpatient ward. Typically, such

pain is suppressed in order to appear the 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 US, individuals with disabilities of all kinds remain seriously under-represented among the ranks of tenured faculty.[9] As has been well-documented with respect to women and members of under-represented 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 do so, mentors, department chairs and others in leadership positions need to commit to actively supporting the retention, promotion, and successful grantsmanship of PD/LE fellows and junior faculty. Many models to support advancement for other under-represented groups have been developed, including targeted fellowships, mentoring programs, and summer training institutes.[8] In psychiatry and allied fields, to the best of our knowledge, no such explicit structures exist for PD/LE researchers.

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 exceptional, efforts to address discrimination in licensure have been led by senior clinicians with lived experience[10] and 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 analogues in efforts to address the lack of inclusion of women and racial/ethnic minorities. For example, board members—whether of a journal or research association—calling attention to the lack of PD/LE representation; or faculty actively questioning 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. The impact of senior thought leaders publicly pushing for greater support and inclusion of those with PD/LE in academic projects, for example, could be far-reaching.

Conclusion

In this Open Forum, we have argued that the actualization of meaningful lived experience involvement in research requires not just inclusion but leadership. We call for greater, and more purposive, investment in building a pipeline of researchers with personal experiences of significant psychiatric disabilities and other target experiences frequently studied in public sector mental health services research. 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 the challenge and act now.

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Table 1. Actionable Steps to Help Build a Diverse Lived Experience Pipeline

Domain	Problem	Actionable Step
Employment	Invisibility or absence of initiatives to proactively hire PD/LE research staff	Visibly and proactively advertise for, recruit and hire undergraduate and post-graduate lab managers, research assistants and other staff
	Underutilization of NIH diversity supplements to support PD/LE individuals	Take advantage of NIH diversity supplements as a mechanism to include and support students and trainees
	Under-representation at the faculty level	Include psychiatric disabilities in faculty diversity initiatives, signal support for applicants with PD/LE, and address discrimination in hiring
Program Admissions	"Red flagging" applicants who mention mental health	Articulate and enforce program policies that preclude any use of psychiatric disabilities for the purposes of disqualification
	Admissions protocols that punish students with disabilities for disrupted academic trajectories	Explicit acknowledgement and allowance of disruptions due to lived experience/disability and reframing of experiences of adversity as diversity assets; removing so called "bright line" disqualifiers to matriculation, such as specific grade point averages or GRE scores
	Absence of visible support for PD/LE applicants	Clearly communicate on websites, admissions materials, etc. that applicants with psychiatric disabilities are welcome, will be supported and accommodations guaranteed
Academic Ableism	Lack of visible support in academic departments and research centers	Senior researchers "speaking out and speaking up" with regard to support for students & junior colleagues (see main text)
	Unhelpful academic accommodations	Provision of academic accommodations that actually meet the needs of individuals with often complex and multifaceted mental health challenges, going well beyond minimal (often physical and sensory disability based) interpretations of the ADA
	Lack of visible role models	Highlighting the accomplishments of, invited speakers, and organizing events featuring successful PD/LE graduate students, postdocs and researchers
	Lack of visible support within professional clinical and training associations	Mental health research and professional associations should include individuals with disclosed PD/LE on boards and committees, develop fellowship and mentoring programs akin to those found for members from under-represented gender and racial/ethnic groups, and publicly signal support on websites and in the planning of conferences and selection of invited speakers
	Deficit-oriented academic cultures	As noted in the main text above, deficit language is often ubiquitous in academic departments, abnormal psychology courses and , especially with respect to "SMIs" such as schizophrenia, and active efforts must be made to de-emphasize deficits and cultivate a deeper understanding of the

Category	Issue	Description
		impact of of such language on PD/LE students, staff and faculty
	Lack of representation on journal editorial boards	As is increasingly common in the UK, journal leadership, including high impact journals, should include researchers with disclosed psychiatric disabilities on editorial boards
	Tokenism when including trainees/researchers with lived experience on grants	When PD/LE researchers or research staff are included on grants, the purpose should not be tokenism or superficial representation, but rather intended to support meaningful contributions, and, where present, consideration of concerns or criticisms with project design, implementation or analysis
Other Prejudice & Discrimination	Micro-aggressions & derogatory language about psychiatric disabilities	Increasing awareness of (unintentional) micro-aggressions, such as ubiquitous references to school shooters as "crazy" in classroom settings, or tolerance of derogatory comments about people with stigmatized diagnoses or addictions (who may in fact be in the room), particularly by instructors, faculty and leadership
	"Benevolent othering"	Increasing awareness of and sharply limiting ostensibly empathetic or benevolent descriptions of PD/LE that in fact reinforce rather than challenge stereotypes about ability, capacity and potential for intellectual contributions
Funding	Glass ceilings with respect to extramural funding	Additional, formal and informal, mentoring and support for PD/LE early career and junior researchers to obtain independent extramural funding
	Lack of dedicated funding for user involvement and leadership	Explicit requirements that stakeholder participation be present in every funded clinical and services grant (as already mandated by the National Institute of Health Research in the UK) and explicit support for service user-led projects and community based participatory research
	NIH does not allow applicants to select "psychiatric disabilities" as their disability category	Rather than placing psychiatric disabilities in a catch-all "other" category, allow applicants to select psychiatric disability as a standalone choice
	Lack of transparent reporting on success rates of applicants with psychiatric disabilities	NIMH, NIDA and other entities funding work on mental health/disability must regularly and transparently report submission and success rates for applicants with disclosed psychiatric disabilities
	Explicit inclusion of proposal reviewers with PD/LE	In parallel with initiatives to increase representation of reviewers from other under-represented groups, researchers with disclosed psychiatric disabilities should be explicitly sought for both ad hoc and standing NIMH/NIDA (and other relevant) review committees