

# Service User Participation Within the Mental Health System: Deepening Engagement

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Over the past decade, there has been a marked uptick in interest in increasing service user participation in the U.S. mental health care system, including clinical practice, research, and policy. Too often, however, these efforts remain superficial and unlikely to bring about the deeper transformation of systems long called for by grassroots activists.

This Open Forum—addressed to mental health administrators, researchers, and clinicians—highlights the importance of considering diverse, critical perspectives and engaging in ways that move beyond purely intellectual rapprochement.

*Psychiatric Services in Advance* (doi: 10.1176/appi.ps.20200494)

In the United States, there has been a marked increase in service user participation across the spectrum of clinical practice, research, and policy in recent years. In theory, such participation schemas are designed to bring about a more equitable, effective, and humane system of care. However, these efforts are often criticized by service user activists as lacking sufficient service user leadership and influence (1–3). In this Open Forum, our aims are twofold: first, to describe limitations of current inclusion efforts, and second, to promote proactive engagement with a plurality of critical perspectives in order to help forge affective and intellectual bonds and to sketch concrete ways in which such engagement might be pursued.

## Limitations to Genuine Collaboration: Co-optation, Siloing, and Tokenistic Involvement

In a recent commentary, British service user research pioneer Peter Beresford described a fundamental tension between system-led efforts oriented toward “information for improvement,” (i.e., utilizing service user feedback for incremental change) and the more intensive service user demand for deep systemic change and greater democratization (1). Although there are clear differences between United Kingdom and U.S. health care systems, with the latter arguably lagging far behind the former in infrastructure development for service user involvement, the same tension is far from unfamiliar in the United States, perhaps most prominently in the integration of peer support into mainstream settings.

In the United States, mutual (or “peer”) support has generally descended from the Civil Rights era organizing

efforts of “ex-patient” and “mad liberation” groups, which sought to establish user-led alternatives to mainstream services and to raise consciousness (4). These early efforts were both inherently political, emphasizing historical and contemporary power hierarchies within mental health policy (and the need to challenge them), and oriented toward the celebration of mental differences, rather than conformity. Thus, early writings in publications such as *Madness Network News* (5) strongly centered on the language of emancipation and pride, rather than on treatment or self-management.

Moving ahead 5 decades, however, the contemporary U.S. peer workforce, numbering in the tens of thousands (6), consists primarily of a class of workers hired at an entry level, often with low wages and minimal or no benefits and limited opportunities for advancement (7). Even where present, peer specialist career ladders generally remain siloed off from other aspects of clinical treatment and quality improvement, such that mid- or senior-level peer supervisors are likely to have limited direct influence over other mainstay treatment modalities. With respect to the actual work performed by peer providers, case management roles remain typical (8), and the neoliberal language of “self-management” has largely overtaken “collective conscientization.” When we turn to the research literature, peer support is not infrequently marketed as a means of improving “treatment engagement” and even “medication adherence” (9), activities largely in opposition to the field’s more radical roots.

In the research sphere, despite increasing theoretical support for stakeholder participation, implementation arguably mirrors much of the above: namely, forms of participation designed to incrementally improve a specific research

project or implementation effort but rarely oriented toward a more fundamental rethinking of what matters and why (10). While the empirical literature on the “state” of U.S. mental health services research remains extremely underdeveloped, anecdotally we (the authors) often hear of service users asked to serve as advisors or consultants on projects in which diversity of representation is minimal to nonexistent—both in the sense of racial-ethnic diversity and diversity of perspectives on the project in question.

In summary, while efforts to be more inclusive are being made, we see co-optation, the creation of “separate and unequal” knowledge and practice siloes, and a lack of deeper engagement with the breadth of perspectives present in service user communities, all of which limit the extent to which service user voices can influence systems change.

### **Moving Beyond the Single Story: Engaging With Grassroots Pluralism**

In her powerful TED Talk, “The Danger of a Single Story,” novelist Chimamanda Ngozi Adichie discusses the epistemic violence perpetrated when the complexity and diversity of groups are reduced to a single narrative, typically from those in power:

There is a word, an Igbo word, that I think about whenever I think about the power structures of the world, and it is “nkali.” It’s a noun that loosely translates to “to be greater than another.” Like our economic and political worlds, stories too are defined by the principle of nkali: How they are told, who tells them, when they’re told, how many stories are told, are really dependent on power. [And] power is the ability not just to tell the story of another person, but to make it the definitive story of that person [or group]. (11)

Users and survivors organize within the context of diverse stories and experiences, with some inevitable tensions between groups. Thus some peer-led initiatives have rallied around the reclamation and celebration of “mad” or “neurodivergent” identities (12), whereas others have focused on challenging extant policy, including contemporary prescribing practices, diagnosis, involuntary interventions, or coercion. Still others have centered on the concomitant oppressions of race, socioeconomic status, and disability, calling for recognition that the same systemic racism that underlies homelessness, poverty, police brutality, and incarceration is inextricably woven into the fabric of the mainstream mental health system (2, 13). Alternatively, other grassroots organizations have advocated for more incremental improvement, with change remaining within a conventional service paradigm, such as campaigns designed to promote help-seeking (e.g., Active Minds, OC87 Recovery Diaries). At the individual level, there are stories of institutionalization, betrayal, and trauma, as well as empathy and restoration; and impairment but also positive identity and pride. As per Adichie, however, mainstream clinical and research communities rarely fully engage with this narrative and experiential diversity.

### **Deep Engagement With Diverse and Challenging Viewpoints Through Affect**

A second aspect of the “deep engagement” that advocates call for is a willingness to embrace, rather than avoid, affect. As Wittgenstein observed: “When [one] reads a poem or narrative with feeling, surely something goes on . . . which does not go on when [one] merely skims the lines for information” (14). When we, as mental health professionals, advocates, and researchers, look to service users for “information” only, we miss the more generative experience of being moved, of opening ourselves up to the stories and experiential knowledge of others, and of appreciating the force of emotion in generating change.

Notably, within the related world of psychotherapy, affect has long held an instrumental role in healing. For example, relational forms of psychotherapy view transformation of *both* the patient and therapist as occurring through the bimodal process of deep listening and mutual empathy (15). Likewise, in many feminist approaches to psychotherapy, which seek to divest the therapist of the role of rescuer in service of a more egalitarian relationship, the client is viewed as the expert of his or her experience, with transformation (i.e., personal and societal) contingent on the development of authentic relationships and the uplifting of marginalized voices. These traditions within the field serve at least as a reminder that we do not neglect or avoid affect when it comes to more dyadic forms of transformation. The potential for powerful affective bonds is also, of course, at the heart of peer support. And yet when considering system planning, design, evaluation, and research, we tend to default to a rationalist paradigm.

### **Concrete Ways Forward**

A series of steps that researchers, administrators, and others might take as individuals or in groups (research centers, institutions, programs) is summarized in an online supplement to this Open Forum. In most cases, engagement does not require any additional funding or resources, and most of the activities are things that most researchers and administrators could do now.

Across these suggested activities, we consistently emphasize both diversity and engagement with critical perspectives. With respect to the latter, our belief is that people tend to have the most to learn not from those who already hold the same views, but from those who do not. Disagreement and difference, that is, help unsettle entrenched beliefs and ways of doing things; they force us to ask hard questions, and they deepen our perspectives and commitments. And this unsettling and deepening is precisely the necessary building block of transformative change. In addition, we suggest ways in which researchers and administrators can develop more informal relationships, ideally friendships, with service users and activists or, at a minimum, engage in ways that push past the exchange of narrow or routine

observations, à la Wittgenstein. That is, the simple but radical step that we propose in this context is to engage others in order to *listen*, and most important, to listen in order to be *moved*. Once moved, we suspect the field would in turn be much better able to tackle the structural and institutional changes that could in turn facilitate addressing other gaps and limitations noted earlier, including persistent power inequities and lack of opportunities for service users and activists to directly participate in high-level decision making.

## Conclusions

In this Open Forum we have called attention to some of the limitations of current stakeholder engagement and participation schemas across the mental health field. While acknowledging that structural and institutional changes are needed, we call for greater engagement with diverse and critical perspectives in ways that move beyond narrowly intellectual or rationalistic rapprochement. We provide concrete examples of ways in which researchers and administrators not already involved with activist communities might engage and in turn, foster system transformation.

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The authors report no financial relationships with commercial interests. Received June 30, 2020; revision received September 9, 2020; accepted November 6, 2020; published online March 4, 2021.

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