

Commentary on “I don’t know how to find my way in the world”: Contributions of User-Led Research to Transforming Mental Health Practice

An Argument for Collaboration in Methods to Help People with Mental Illness

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The paper by Larry Davidson and colleagues is very interesting and relevant to ensuring that the consumer voice is represented directly in research. It vividly describes the challenges and aspirations of mental health consumers by outlining their priorities for recovery. For the purposes of this *Commentary*, I’d like to focus on three major areas where I think this paper offers a significant contribution. The first involves the type of methodology - community participatory research - and its value in mental health. Secondly, I think it is imperative to include the end stage user/beneficiary of the research in every step of the research process. And lastly, this paper offers important implications for further applications particularly in the use of these methods in conjunction with more conventional quantitative methods.

The consumer movement in America has been evolving over the last thirty years from one primarily focused on advocacy, particularly protection for people served by the mental health system, to a much broader agenda including direct involvement in the public policy arena. Over these years, we’ve seen state governments adopt consumer affairs offices, and major federal agencies such

as the Substance Abuse and Mental Health Services Administration (SAMHSA) have created an office of consumer affairs in their upper management. And there are other striking and concrete examples of the importance of the consumer voice in determining policies and practices. Out of this development is emerging a system much more conscious of the views, rights, values, and aspirations of people living with mental illnesses. This movement of self-determination, of taking charge of their lives, has been, in my view, one of the major innovations in improving mental health care delivery. It has not always been easy or smooth reconciling the different objectives and priorities of providers, policy makers, and consumers—it has been complicated and sometimes fractious. But over the past decade, we’ve seen a trend emerging of a growing mutual respect and recognition that a well-functioning mental health system needs all the major players—consumers, providers, family members, advocates—represented in any significant discussion. The unique perspectives of the various parties have added richness to debates and contributed to greater innovation.

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Research Methodology

Community participatory research (CPR) is an exciting innovation in research methods that highlights the important role of the community and its members. It represents a form of qualitative research that focuses on outcomes that are relevant to consumers' lives. One strength of this method is the collaborative nature of engaging community members and researchers in the development and execution of the research. This method provides for a feedback loop where information is gathered from a community, analyzed, and returned to the community for application.

Involvement of Beneficiary in Research Process

In recent years, there's been an emerging interest in consumer-driven programming. This paper demonstrates the very centrality of the lived experience, which is critical to understanding the actual life circumstances of an individual and how they influence their ability to negotiate their world. This work is by consumers for consumers but of great value to clinicians and others.

In quantitative research, personal experience is organized into objective categories that cannot capture the richness of the consumer's personal experience. The paper effectively demonstrates the power of the narrative, the description of these experiences in one's own words.

For example, we are vividly reminded in the "Findings" portion of the multiple profound losses some consumers suffer and the cumulative influence these factors have on a person's ability to function in the community. The authors clearly describe the complexity involved in trying to fully understand the many factors of and impediments to recovery, particularly poverty, isolation, and loneliness.

The authors also point out the potential disconnect between therapeutic goals,

such as symptom reduction and improved functioning, from the very practical instrumental needs of everyday life. In reality, they cannot be separated.

The community participatory method of research is empowering. It recognizes and respects the challenges faced by consumers on a daily basis. The very structure of the questions is respectful. The authors did not rely on the more traditional review of the record, nor did they require the filling out of forms. The questions asked were open-ended so the interviewees were not confined by narrow responses.

Future Applications

This study by Davidson and his colleagues presents a strong argument for the importance and relevance of community participatory research, organized and conducted by consumers with guidance from an established researcher. It is an important contribution to understanding the challenges and barriers faced by people living with mental illness. The use of community participatory research does not represent an either/or quantitative versus qualitative debate. It is important to find ways that the benefits of both quantitative and qualitative methods can be integrated or at least made complementary to the recovery experience.

The authors have done well to inform us of the explicit challenges and barriers faced by people with mental illness. We need to explore the collaborative benefits of well-controlled studies so that we may better address the findings and generalizability of results to other populations. It is unfortunate that many of the more conventional funding enterprises clearly favor the classic quantitative methodological approach, the randomized control trial. We need more integrated methodologies that capture the strengths of personal experience while offering guidance in an intellectually honest and rigorous way.