

# Bringing Recovery and Consumers' Views Into the Mainstream of Mental Health Quality Measurement

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Health policies in the United States and elsewhere are moving to increase accountability of health care systems and providers for providing high-quality, efficient care and driving application of evidence-based improvement strategies. To support these efforts, a "quality measurement industrial complex" has been created to develop, endorse, and apply quality measures that incentivize these behaviors. Parallel to this development in mental health care is an emerging commitment to include recovery orientation approaches in

treating serious mental illness. However, consumers have been only tangentially involved in quality assessment and improvement strategies of the mental health services that they are receiving. This Open Forum aims to advance the conversation about how to integrate recovery into mental health care quality assessment cohesively and how to involve consumers in this process in a more meaningful way.

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Over the past decade, health policies in the United States and other countries have moved to increase accountability of health care systems for providing high-quality, efficient care that achieves improved outcomes. In fact, an entire "quality measurement industrial complex" has been developed to support this accountability enterprise and includes measure developers (typically professional associations, accreditation organizations, or government contractors), evidence developers (researchers and research funders), measure endorsers (the National Quality Forum), and measure users across multiple stakeholders (Centers for Medicare and Medicaid Services, insurers, state officials, employers, and the public).

With regard to quality measures that address outcomes, adequate measurement depends on having agreement on what the desired outcomes are. In mental health quality measurement, recent efforts have largely focused on symptom measures (such as the Patient Health Questionnaire–9 [PHQ-9]). Moreover, there is no consensus, nationally or internationally, on quality measures that reflect recovery concepts at the consumer or service provider level or on how to effectively and consistently incorporate these measures into broader quality improvement and accountability strategies. The concept of recovery places the consumer's views and experiences, including how one feels about the design and delivery of treatment, at the center of evaluating outcomes of mental health interventions. Consumers' perspectives could serve as an important linkage between two seemingly opposing ways of how the mental health care system defines and measures outcomes. The goal of this Open Forum is to advance the conversation about how to introduce recovery

into mental health care assessment cohesively and how to involve consumers in this process in a meaningful way.

## Moving Beyond the Traditional Outcomes Paradigm

A recovery orientation is increasingly recognized as one of the key domains of quality in mental health care (1). Provider organizations and mental health systems have begun to develop and implement recovery frameworks and programs, signaling a shift in mental health policy and its underlying principles and values (for example, the efforts of the Substance Abuse and Mental Health Services Administration [SAMHSA] to implement recovery-oriented behavioral health services nationwide through national training and technical assistance projects and pilot-testing recovery tools). Existing quality measures that focus on outcomes, however, largely concentrate on symptomatic change (such as the PHQ-9 and Global Assessment of Functioning), quality of life (36-Item Short-Form Health Survey, EuroQol Five Dimensions Questionnaire), or multiple dimensions incorporating functional, social, and symptomatic change (Health of the Nation Outcome Scales, World Health Organization Disability Assessment Schedule). There is a noteworthy distinction between using clinical outcome assessment tools for clinical or research purposes and using quality indicators for holding providers or health care systems accountable for their outcomes; the latter is much more complex and relies on outcomes measurement based on clearly defined numerator and denominator definitions and the need for baseline measurement and risk adjustment.

Overall, the concept of recovery is less well measured, at both the personal and the organizational or system level. This is partially because of the lack of consensus about what recovery means, both for an individual's personal recovery and the recovery orientation of health services and systems at large. As a result, existing measures show a broad variety of definitions and underlying concepts of recovery (2) and what constitutes recovery-oriented services.

For example, the CHIME (representing connectedness, hope and optimism, development of positive identity, meaningfulness in life, and empowerment) framework (3), provides a systematic overview and synthesis of people's experiences of recovery and could present an empirical basis for future recovery-oriented research and practice to inform the development of recovery outcomes measures. The categories of this framework, however, only partially overlap with the ten guiding principles of recovery developed by SAMHSA, underscoring the need for a broader consensus on recovery concepts and measurement. While there is general agreement that organizational and structural transformation is needed to develop recovery orientation within health service delivery systems, there is less agreement on structural components that would enhance the capacity of organizations and providers to offer care that achieves recovery outcomes of service users. However, if we want to bring recovery outcomes measurement into the mainstream of quality measurement, the field must articulate what we are going to measure and how we are going to measure it.

### **Integrating Recovery in the Broader Outcomes and Quality Measurement Endeavor**

The quality improvement strategy for the behavioral health field, laid out by the Institute of Medicine in 2006 (4) and reinforced in its 2015 report "Psychosocial Interventions for Mental and Substance Use Disorders" (5), includes several steps that can be applied to the concept of recovery to bring it into the mainstream of behavioral health measurement: filling gaps in the evidence base for effective recovery-oriented care and practices; training clinicians to deliver recovery-oriented health care; providing stewardship to develop and implement recovery-oriented quality indicators, including supplying sufficient resources to do so; bringing behavioral health into the mainstream of health information technology; and incorporating routine quality and recovery measurement into day-to-day processes of behavioral health organizations and providers.

### **Strengthening Consumer Participation in the "Quality Measurement Industrial Complex"**

Consumer advocacy groups and individuals with mental illness should be involved throughout the process of implementing new services and policies to ensure meaningful input into ever more complex health care systems and the regulatory and accountability programs that surround them. However, the push for increased involvement and participation of consumers

will require a combination of strategies to build the mechanisms that enable and support a meaningful role for consumers. The overall structures and processes by which quality measures in the United States are prioritized, developed, vetted, implemented, and used are highly complex and not well understood by most health care professionals, let alone mental health consumers. Although the National Quality Forum's consensus process for quality measure endorsement (6) and the Affordable Care Act's mandated Measure Applications Partnership annual review of proposed measures both incorporate involvement of multiple stakeholders and fully transparent criteria and processes (7), mental health consumers are rarely involved in (or aware of) the decisions at each step of the process.

### **Preparing Consumers to Be Effective Participants**

Throughout scientific meetings, conferences, and discussion forums, service users are often represented by a single representative ("the lone voice") to provide a consumer perspective amid a much larger group of representatives of medical and other health care professionals, such as psychiatrists, psychologists, nurses, social workers, and administrators. Against this reality, it will be important to leverage consumer advocates' roles by strengthening consumer education and training as well as advocacy and leadership skills.

This capacity building will require sustainable funding, which may open a role for public-private partnerships. For example, the Genio Project from Ireland has brought together government and philanthropy to develop a multipronged model that incorporates capacity building among key stakeholders, with special focus on service users and their families and friends, to build the skills and leadership to successfully advocate for the support they require and implement necessary changes (8).

In the United States, advocacy groups such as Community Catalyst (9) are seeking to enhance the impact and build the power of state and local leaders and communities engaged in health advocacy, particularly those representing the most vulnerable and underserved constituencies, through education and by providing tools and support to help them achieve their goals. A recent RAND report, sponsored by the Community Catalyst Center for Consumer Engagement in Health Innovation (10), explores the experience of consumer advocates in engaging with quality measurement and identifies barriers to effective consumer engagement and ways to address them. The report describes the processes within the quality measurement industrial complex in consumer-friendly language and addresses recommendations to both quality measurement leaders and consumer advocates to enhance consumer engagement in those processes.

### **Strengthening Recovery Research and Consumer Participation in That Work**

Evidence-based measurement requires evidence, which means that expanded resources are needed to bolster further research into developing more valid, feasible, and useful quality measures

that incorporate recovery concepts. This also means that people with mental illnesses should have a larger role within the mental health care system, especially in relation to early-stage research activities to develop recovery-oriented services and measures. The James Lind Alliance in England has developed a formalized consensus process, bringing consumer, caregiver, and clinician groups together on equal footing to identify research priorities that are important to all groups (11). Such an approach might be used here in the United States.

Bringing recovery into the mainstream of quality measurement and tying the various components into a cohesive, inclusive strategy will require leadership, adequate resources, and a meaningful collaboration between consumers, providers, and the research community.

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