Executive Summary: Measures That Matter

Embedding Measures That Matter Into Mental Health Systems: A Lived Experience-Informed Measurement Framework for Serious Mental Illness and Guidance for Future Initiatives

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FOUNTAIN HOUSE

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Purpose and Vision

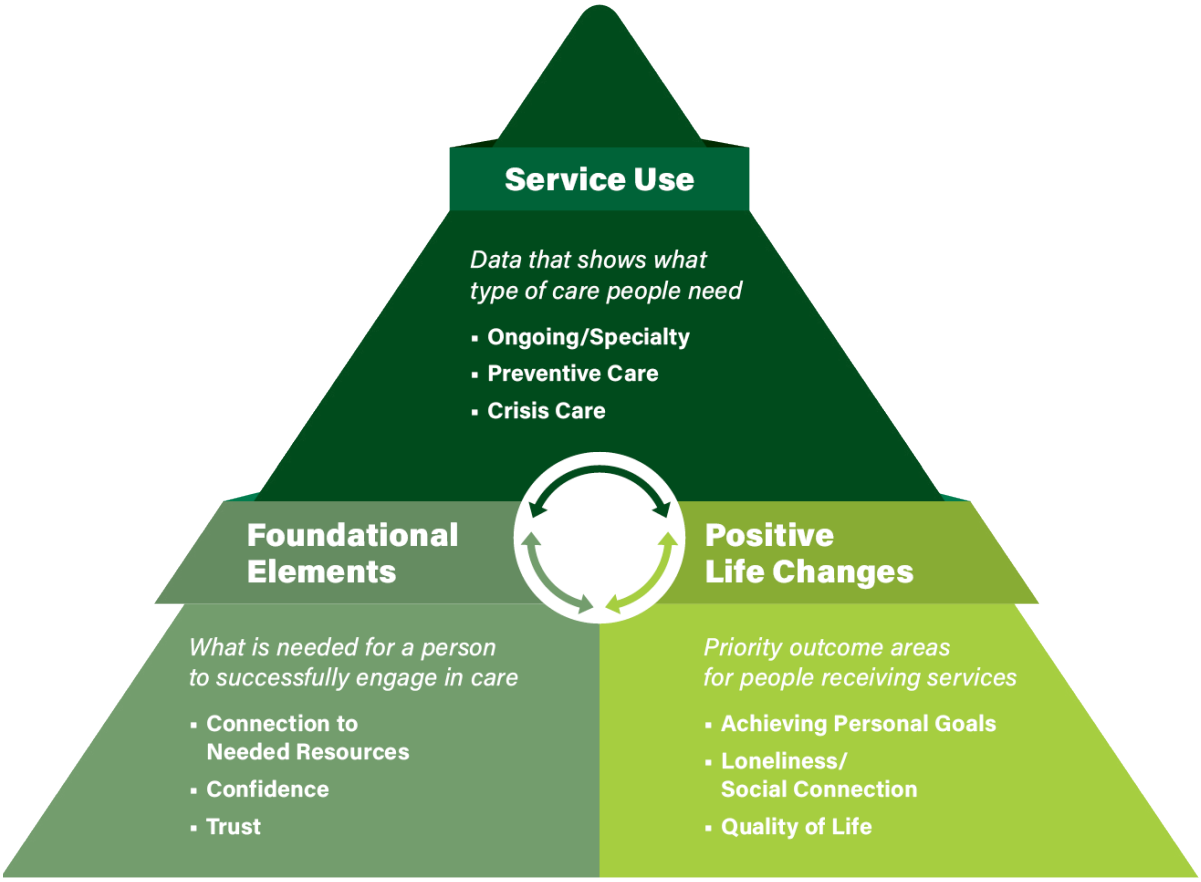
Across the United States, the behavioral health care system has struggled to consistently measure outcomes that truly reflect the needs and goals of people living with serious mental illness.[1] Systems generally measure what's easy to measure more so than measuring what really matters, leading to a system that inadequately meets the needs of those it aims to serve. While clinical data, such as hospitalizations and measures of basic functioning, are commonly tracked, many critical aspects of recovery — like social support, trust, personal goals and basic needs — are often overlooked. Ultimately, what gets measured gets done; aligning measurement with the real priorities of individuals with serious mental illness could significantly improve care quality and efficiency.

The Measures That Matter project has worked with people with lived experience of serious mental illness to explore what matters most to them across their recovery journeys. The project gathered input from more than 100 people with lived experience through working groups, focus groups, and a lived-experience survey, as well as key stakeholder interviews with 15 additional experts in measurement science, clinical care, payer systems, and policy. This project introduces a **measurement framework for serious mental Illness**, which presents the measurement domains and constructs that research suggests matter most for individuals with serious mental illness, as well as exemplar measurement tools. This framework was informed directly by individuals with lived experience of serious mental illness. The project also offers **implementation guidance**, which discusses practical considerations to support the adoption of this framework in real-world care settings, with attention to reducing provider burden, increasing stakeholder buy-in and aligning system incentives.

1 Fountain House is aware that there are many different views about the semantics of serious mental illness among people with lived experience. When the Fountain House community engaged with members about how to refer to it in public conversation, consensus emerged to use the term serious mental illness even as some members prefer other terms. We defer to the collective views of our community of people of lived experience.

Measurement Framework

The framework organizes key measures into three core domains; **foundational elements, positive life changes** and **service use**. Our measurement framework is centered on the idea that individuals with serious mental illness often have different needs at different stages of their recovery. This concept has been central in creating a framework that starts with what is most important to engage (foundational elements) and builds into further measures.



Foundational elements provide insight on whether people with serious mental illness are being provided with a strong baseline for recovery and rehabilitation. The positive life changes category, often described in the measurement world as patient-reported outcome measures (PROMs), assess the extent to which they are achieving their most desired outcomes — the key benefits they want to achieve. Finally, service use describes the utilization outcomes that demonstrate the impact of those benefits in terms of how people use the health care system — how much are they moving services upstream that allow them to avoid unnecessary crisis care downstream.

A. Foundational Elements

The framework identifies three key measure constructs, which emphasize critical factors that are necessary to assess whether individuals with serious mental illness have the baseline conditions in place to support their recovery. The key foundational element constructs are trust, basic needs (e.g., referrals to housing, food security, employment, etc.) and confidence (which includes agency and self-efficacy).

B. Positive Life Changes

In addition to foundational elements, the framework highlights three key self-reported outcome constructs, which reflect outcomes that the person receiving care self-reports on. These self-reported outcomes are constructs many people with lived experience emphasized as most important in their recovery, including quality of life, loneliness/social connection and personal goal attainment.

C. Service Use

Service use data can be useful to understand how a person with serious mental illness uses different care options. The framework highlights aspects of crisis care (e.g., hospitalizations, ER visits), ongoing treatment (e.g., specialty care, ongoing therapy), and preventive care (e.g., attendance at a community-based organization, primary care visits) measurement.

The framework also provides two or three specific example measures within each construct with the expectation that only one measure will ultimately be used for each construct.

Implementation Guidance

The implementation guidance offers practical considerations to guide application of the measurement framework to different serious mental illness care settings and emphasizes some key leverage points for integration into current care delivery systems across the U.S.

Implementation of the framework includes two fundamental categories. First, to have an impact, the framework needs to be embedded into payment programs, including value-based payment (VBP) models and other private and public payer and purchaser initiatives that offer high leverage for changing behavior of health system actors. History suggests that performance measures can influence provider and health plan behavior if they are tied to significant financial gains or losses. The guidance provides insight into various federal, state and local opportunities that provide high leverage points for VBP integration.

Second, incorporating new, important measures into provider and health plan workflows requires making the right thing the easy thing to do. Technology that efficiently embeds measures into existing data systems and workflows can help ease the burden placed on providers. In addition, emerging technologies such as artificial intelligence (AI) could conceivably make passive data collection of PROMs less burdensome and offer fewer interruptions for providers and the people they serve, if that is done in ways that safely protect their personal data.