

What We Measure Matters: Centering Lived Experience in Developing Behavioral Health Quality Measures

By Christopher Menschner, Center for Health Care Strategies, and Amy Brinkley, National Association of State Mental Health Program Directors

KEY TAKEAWAYS

- Partnering with people with lived experience[†] in developing behavioral health quality measures can help improve service quality and provider and payer accountability.
- Best practices are emerging for partnering with people with lived experience in shaping behavioral health policy, program design, and quality measures.
- There are unique factors important to people with lived experience that should be considered in developing behavioral health quality measures.

In 2023, 23 percent of adults in the U.S. reported experiencing a mental illness, totaling more than 58 million Americans.¹ Of those 58 million, 46 percent reported not receiving treatment. During the same period, 17 percent of adults across the nation reported experiencing substance use disorder, yet three out of four did not receive treatment.² The need for services far outpaces access for the general public, and significant disparities exist in access to treatment and outcomes for certain racial and ethnic groups.^{3,4}

Increasing the *quantity* of behavioral health services (i.e., number of providers, appointment slots) is key to addressing the nation's behavioral health crisis. However, it is also critical that both existing and expanded services are high *quality*, as defined not only by providers and payers, but also by people with lived experience of behavioral health needs. Existing quality measure frameworks have been developed primarily from a payer and provider perspective and have not meaningfully recognized the perspectives of people with lived experience.



Developed in Partnership with People with Lived Experience

This resource was developed in partnership with a group of consultants who have lived experience with behavioral health needs and current or prior experience working in state behavioral health agencies and/or national behavioral health organizations. CHCS is grateful to them for their thoughtful review and contributions: **Cheri Bragg, Amy Brinkley, Dana Foglesong, Brandy Martinez Hemsley, Deandre Kenyanjui, Luis Tony Sanchez, and Steve Allen.** Our collaboration has strengthened our commitment to engaging people with lived experience to improve the behavioral health system.

[†]Note, the term 'people with lived experience' is used throughout this document, which is intended to be inclusive of 'lived expertise.' See box on page 2 for definitions of the terms.

Partnering with people with lived experience in designing behavioral health quality measures ensures that improvement efforts focus on what matters most to those seeking care. It can hold health systems and providers accountable for developing care models that align with patient needs, fostering increased patient engagement and potentially improving health outcomes.^{5,6} This brief summarizes the current state of behavioral health quality measures, promising measurement approaches that reflect the perspectives of people with lived experience, considerations for developing quality measures in a behavioral health context, and suggested measurement domains.

Existing Behavioral Health Quality Measures

As illustrated in Exhibit 1 (next page), existing behavioral health quality measures are largely clinical in nature, with a focus on areas like symptom improvement, avoidance of hospitalizations, and adherence to treatment plans. Clinical quality measures provide key information on specific aspects of a person’s care and progress toward wellness. They also provide payers with the information necessary to determine and manage the cost of care. However, they should be balanced by additional quality measures that assess other aspects of care important to people participating in services. A more balanced approach that includes markers of clinically effective care and positive care experience that are defined by the person participating in care (referred to in this brief as ‘service participant’), can provide a more meaningful standard of quality and progress toward wellness goals.

Understanding Lived Experience and Lived Expertise

In this brief, we define “lived experience” and “lived expertise” as follows:

- **Lived experience:** Firsthand experience of a behavioral health condition and experience receiving behavioral health services. This experience provides valuable insights into how services are delivered and the challenges one may face when navigating the behavioral health delivery system.
- **Lived expertise:** Deep knowledge that people with lived experience can develop about behavioral health and the behavioral health delivery system. This term recognizes that lived experience is dynamic and that expertise can grow over time through engaging in program and policy discussions, as well as learning more about how the system operates and how policies are developed and implemented.

Note that the term “people with lived experience” is used throughout this document, which is intended to include lived expertise.

Exhibit 1. Select Existing Behavioral Health Care Quality Measures

FOCUS AREA	MEASURE NAME	MEASURE STEWARD	USE IN SELECT PROGRAMS	
			2023/2024 CMS Medicaid Adult Core Set	2023/2024 CMS Medicaid Child Core Set
Depression	Screening for Depression and Follow-Up Plan	CMS	✓	✓
	Antidepressant Medication Management	NCQA	✓	
Follow-up	Follow-Up After Hospitalization for Mental Illness	NCQA	✓	✓
	Follow-Up After Emergency Department Visit for Mental Illness	NCQA	✓	✓
	Follow-Up After Emergency Department Visit for Substance Use	NCQA	✓	✓
	Follow-Up Care for Children Prescribed Attention Deficit/Hyperactivity Disorder Medication	NCQA		✓
Serious Mental Illness	Adherence to Antipsychotic Medications for Individuals with Schizophrenia	NCQA	✓	
	Diabetes Screening for People with Schizophrenia or Bipolar Disorder Who Are Using Antipsychotic Medications	NCQA	✓	
	Diabetes Care for People with Serious Mental Illness: Hemoglobin A1c Poor Control (>9.0%)	NCQA	✓	
	Use of First-line Psychosocial Care for Children and Adolescents on Antipsychotics	NCQA		✓
	Metabolic Monitoring for Children and Adolescents on Antipsychotics	NCQA		✓
Substance Use	Medical Assistance with Smoking and Tobacco Use Cessation	NCQA	✓	
	Use of Pharmacotherapy for Opioid Use Disorder	CMS	✓	
	Initiation and Engagement of Substance Use Disorder Treatment	NCQA	✓	

Note: A ✓ indicates use in the program, though some measures may vary slightly across programs, e.g., different available data sources for different reporting entities. Source: <https://www.ncqa.org/wp-content/uploads/NCQA-BehavioralHealthCareIntegration-Whitepaper-WEB.pdf>.

Promising Momentum for Engaging People with Lived Experience

In recent years, a number of initiatives have aimed to better engage people with lived experience in developing behavioral health quality measurement frameworks. In a 2021 report, the National Committee for Quality Assurance (NCQA) stated: “*The current fragmented and inequitable state of behavioral health care calls for a quality measurement framework that can be used to guide and hold entities jointly accountable for improving care access and outcomes for individuals with behavioral health conditions.*”⁷ Partnering with people with lived experience in designing new quality measurement frameworks would center participant experience, facilitate participant-defined concepts of wellness, and ultimately set providers and service participants up for increased success.

In 2021, NCQA issued a *Behavioral Health Quality Framework: A Roadmap for Using Measurement to Promote Joint Accountability and Whole-Person Care*.⁸ As part of ongoing efforts, from 2022 to 2024, NCQA led a learning collaborative of certified community behavioral health clinics to evaluate the feasibility and effectiveness of a person-centered outcomes approach.⁹ Participants reported that using these measures enhanced patient engagement and helped providers identify goals, supporting discussions with patients to help them meet their goals.

In May 2023, the Substance Abuse and Mental Health Services Administration (SAMHSA) issued a policy requiring all SAMHSA activities to be fully inclusive of people with lived experience.¹⁰ In announcing the policy, SAMHSA stated “*people with lived experience are fundamental to improving mental health and substance use services and should be meaningfully involved in the planning, delivery, administration, evaluation, and policy development of services and supports to improve our processes and outcomes.*” In June 2023, SAMHSA’s Office of Recovery convened a *Recovery Research Technical Expert Panel*, which included recovery community leaders with lived experience.¹¹ The panel, tasked with informing the design of a national recovery research agenda, focused on quality measurement. Select takeaways included opportunities to:

- Prioritize more in-depth care experience surveys that offer greater opportunity for service participants to convey their experience in greater detail and move away from care satisfaction surveys that offer limited opportunity for robust input.
- Ensure that surveys are culturally specific since aspects of the care experience are likely to vary across racial and ethnic groups.
- Use peers to administer care experience surveys to promote more open and honest responses.
- Invest in developing measures that can be used in behavioral health value-based payment environments.

This progress aligns with recent efforts to inform policies and programs by incorporating the perspectives of people with lived experience, both in behavioral health specifically and in health care more generally. In April 2024, the Centers for Medicare & Medicaid Services issued a final rule requiring states to establish a member-only advisory group or *Beneficiary Advisory Council* (BAC), which is to be comprised solely of Medicaid members, their families, and/or other caregivers.¹² The rule intends to create a “comfortable, supporting, and trusting environment” where BAC members can offer input freely in a safe environment. BACs are not specific to behavioral health, but early activities around BAC formation indicate that some states prioritize including people with lived experience of behavioral health needs to ensure their perspectives are considered. This is especially important given that Medicaid is the country’s single largest payer of mental health services.¹³

Considerations for Developing Behavioral Health Quality Measures

Engaging in behavioral health services is a deeply personal experience and involves high levels of vulnerability. It often requires individuals to discuss difficult past experiences. Further, what is shared by someone participating in services may have serious implications, such as child welfare agency involvement, police interaction, and involuntary hospitalization, making the stakes of certain care interactions very high.

Trust is the cornerstone of any positive relationship and is especially critical in a clinical behavioral health services context. Other key elements of successful provider-service participant relationships include, for example, shared decision-making authority, respectful communication, and transparency. These key elements significantly enhance experiences in behavioral health services, promote engagement in treatment, and are likely to improve care outcomes.¹⁴ Given their importance, it is critical to include these relational factors in quality measurement frameworks. While these elements contribute to effective therapeutic relationships, additional quality measures should focus on individual goals and experiences, recognizing the specific aspects of care that matter most to each person.

Quality measures that prioritize the perspectives of patients often rely on self-reporting methods, such as surveys, questionnaires, and direct verbal feedback. These data collection techniques are valuable for health care quality measurement, especially in behavioral health. However, due to stigma, people with lived experience with behavioral needs may be viewed as less credible. For these measures to be effective, it is essential that people participating in services feel trusted and respected when sharing their experiences. While the focus is often on the trust between participants and providers, it is equally important for providers and payers to trust care recipients’ accounts of their care experiences.

Areas of Focus for a Reimagined Approach to Behavioral Health Measurement

Building on recent efforts and drawing from discussions with CHCS' partners with lived experience, we propose the following focus areas for developing new behavioral health quality frameworks. It is important to note that these are broad themes. Specific measures should be developed in partnership with people participating in services to ensure that they are relevant and represent meaningful measures of progress and wellness.

Potential Measurement Domains

1. Quality of Life

- Service participants determine what improved “quality of life” looks like and means to them to serve as a framework for goals and objectives.
- The degree to which addressing health-related social needs is integrated into strategies for achieving overall goals and meeting urgent basic needs.

2. Personalized Care Approaches

- Service participants determine what treatment options, whether traditional or non-traditional, other wellness activities, or some combination of all, are most helpful to them and develop care plans accordingly.

3. Holistic Assessment of Progress and Wellness

- Progress and wellness are assessed not just by reducing symptoms, but by service participant-defined measures that prioritize what matters most to them and take a holistic approach to progress and wellness (e.g., sense of agency, belief in ability to make progress).

4. Bidirectional Trust and Credibility Between Service Provider and Participant

- The degree to which service participants trust providers and feel they are trusted and seen as credible by providers.

5. Dignity and Respect

- Service participants feel they are spoken to, and generally treated with dignity and respect, with no stigmatization or discrimination.

Conclusion

New momentum is building, from federal agencies to communities nationwide, emphasizing the importance of centering community voices in policy and program design. This includes efforts to partner with people with lived experience to develop more effective behavioral health quality measurement approaches. Involving individuals who use behavioral health services in defining quality standards can potentially improve outcomes, lower costs, drive more equitable care, and shape behavioral health services in an unprecedented way with the quality of services defined by what matters most to the people participating in them.



ABOUT THE CENTER FOR HEALTH CARE STRATEGIES

The Center for Health Care Strategies (CHCS) is a policy design and implementation partner devoted to improving outcomes for people enrolled in Medicaid. CHCS supports partners across sectors and disciplines to make more effective, efficient, and equitable care possible for millions of people across the nation. For more information, visit www.chcs.org.

ENDNOTES

¹ Substance Abuse and Mental Health Services Administration. Highlights for the 2023 National Survey on Drug Use and Health. 2023. U.S. Department of Health and Human Services.

<https://www.samhsa.gov/data/sites/default/files/NSDUH%202023%20Annual%20Release/2023-nsduh-main-highlights.pdf>

² Substance Abuse and Mental Health Services Administration. Highlights for the 2023 National Survey on Drug Use and Health. U.S. Department Health and Human Services.

³ Hundrup, A. (2024, March 5). The Mismatch between Mental Health Care Access and Demand. *Watchblog: Following the Federal Dollar*. <https://www.gao.gov/blog/mismatch-between-mental-health-care-access-and-demand>

⁴ Panchal, N., Hill, L., Artiga, S., Hamel, L. (2024, May 23). Racial and Ethnic Disparities in Mental Health Care: Findings from the KFF Survey of Racism, Discrimination and Health. <https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-and-ethnic-disparities-in-mental-health-care-findings-from-the-kff-survey-of-racism-discrimination-and-health/>

⁵ National Committee for Quality Assurance. (n.d.). *Person Centered Outcome Measures*. <https://www.ncqa.org/hedis/reports-and-research/pco-measures/>

⁶ O'Mara-Eves, A., Brunton, G., Oliver, S. et al. The effectiveness of community engagement in public health interventions for disadvantaged groups: a meta-analysis. *BMC Public Health* 15, 129 (2015). <https://doi.org/10.1186/s12889-015-1352-y>

⁷ Niles, L., Olin, S. (2021, May). *Behavioral Health Quality Framework: A Roadmap for Using Measurement to Promote Joint Accountability and Whole-Person Care*. National Committee for Quality Assurance. https://www.ncqa.org/wp-content/uploads/2021/07/20210701_Behavioral_Health_Quality_Framework_NCQA_White_Paper.pdf

⁸ Niles, L., Olin, S. (2021, May). *Behavioral Health Quality Framework: A Roadmap for Using Measurement to Promote Joint Accountability and Whole-Person Care*.

⁹ National Committee for Quality Assurance. (n.d.). *Person-Centered Outcome Measures*. <https://www.ncqa.org/hedis/reports-and-research/pco-measures/>

¹⁰ Substance Abuse and Mental Health Services Administration. (2023, May). Policy on the Inclusion of People with Lived Experience. U.S. Department Health and Human Services. <https://www.samhsa.gov/sites/default/files/inclusion-policy-tc.pdf>

¹¹ Substance Abuse and Mental Health Services Administration. (n.d.) *Recovery Research Technical Expert Panel: Executive Summary and Report*. U.S. Department Health and Human Services. <https://www.samhsa.gov/sites/default/files/recovery-research-technical-expert-panel-executive-summary-report.pdf>

¹² Centers for Medicare & Medicaid Services. (2024, April). *Ensuring Access to Medicaid Services Final Rule*. U.S. Department of Health and Human Services. <https://www.cms.gov/newsroom/fact-sheets/ensuring-access-medicaid-services-final-rule-cms-2442-f>

¹³ Centers for Medicare & Medicaid Services. (n.d.). Behavioral Health Services. U.S. Department of Health and Human Services. <https://www.medicaid.gov/medicaid/benefits/behavioral-health-services/index.html>

¹⁴ Stubbe D. E. (2018). The Therapeutic Alliance: The Fundamental Element of Psychotherapy. *Focus* (American Psychiatric Publishing), 16(4), 402–403. <https://doi.org/10.1176/appi.focus.20180022>