

Making the Case for Engaging People with Lived Experience in State Behavioral Health Reform

By Vanessa Finisse, Center for Health Care Strategies

TAKEAWAYS

- As state leaders explore strategies to reform public behavioral health systems, engaging with people with lived experience is crucial to ensure better outcomes in programs and policies.
- State leaders in behavioral health agencies can play a vital role in championing community and member engagement, but they must first buy into its value.
- This brief makes the case for engaging people with lived experience in state policy and program discussions, outlines strategies to secure leadership buy-in for member and community engagement, and shares messaging tips to address common concerns regarding engagement efforts.

Across the nation, state policymakers are seeking solutions to address the persistent challenges within behavioral health delivery systems. There are high rates of overdose and overdose deaths, high suicide rates, unmet care needs, and an increase in homelessness among individuals with serious mental illness.¹ Many states face significant disparities in behavioral health access and outcomes for people of color and other historically marginalized groups.²

Current state efforts to address systemic issues and promote behavioral health equity are often overseen by system leaders, but they typically do not prioritize engagement with individuals directly affected by these issues. Involving people with lived experience* in policy and program development allows states to hear directly from community members about their experiences with the behavioral health system and challenges with accessing care. It increases the likelihood that identified solutions will meet their needs. The Substance Abuse and Mental Health Services Administration (SAMHSA) mandates that state behavioral health agencies establish mental health planning councils with at least 50 percent representation from people with lived experience and



* 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 3 for definitions of the terms.

their families.³ Additionally, recent Centers for Medicare & Medicaid Services (CMS) requirements for new Medicaid member advisory bodies emphasize the importance of engaging people with lived experience in policy and program development, calling for states to align with these federal priorities and invest in community and member engagement.⁴

Under the *Supporting State Behavioral Health Systems Transformation* initiative, the Center for Health Care Strategies (CHCS) partnered with a group of consultants with lived experience of behavioral health conditions as well as experience working in state behavioral health agencies and/or national behavioral health organizations to co-develop resources for state officials and policymakers within behavioral health agencies. **This brief presents our collective insights on the importance of engaging people with lived experience**, offers recommendations for addressing common concerns about engagement, and outlines strategies to foster leadership buy-in for engaging individuals with lived experience to support behavioral health transformation.

Developed in Partnership with People with Lived Experience

This resource was developed in close partnership with a group of consultants who have lived experience with behavioral health needs and either current or prior experience working in state behavioral health agencies and/or national behavioral health organizations. CHCS is grateful to the following individuals for their partnership, 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 and expertise to improve the behavioral health system, particularly for Medicaid members who face significant challenges in accessing and receiving equitable care.

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, the term “people with lived experience” is used throughout this document, which is intended to be inclusive of lived expertise.

Recruiting People with Lived Experience

While it is important to align on language use, it is equally crucial to recognize that lived experience can mean different things to different people. Here are considerations for state agencies when recruiting for engagement efforts:

- **Clearly define your target audience and purpose.** For example, a state may seek individuals with direct, first-hand experience with a particular issue or service. Think about the role and contributions of the individuals you are seeking to engage.
- **Consider the perspectives and voices** that would help us better understand a service, program, or policy.
- **Encourage individuals to define their lived experience** and their goals for engagement. Avoid pressuring individuals to share their diagnosis or any other information they are uncomfortable sharing.
- **Embrace inclusivity.** Acknowledge and value contributions from individuals with diverse lived experiences. Avoid imposing strict criteria on what is considered relevant or valuable.

Engaging with people with lived experience begins with valuing the diverse perspectives that individuals and families navigating systems bring to the table and committing to include a range of perspectives, especially those most impacted by systemic issues.

The Importance of Engaging with People with Lived Experience in Behavioral Health Reforms

For over a century, people with lived experience of behavioral health conditions have made significant contributions to the mental health system, most notably through the decades-long consumer, survivor, and ex-patient advocacy movement. This involvement began with groups like the Alleged Lunatics' Friend Society, created in 1845 to advocate against human and civil rights violations within mental health care institutions.⁵ Over the years, this advocacy movement has influenced state and federal behavioral health authorities to fund community-based support programs, establish Offices of Consumer Affairs or Recovery Services in many states, and create consumer advisory councils to inform service delivery and policy design.⁶ Engaging people with lived experience has advanced peer support programs and guided the behavioral health field toward greater emphasis on recovery-oriented care, individual empowerment, and patient-centered care.⁷ People with lived experience have improved mental health services and redefined mental health policy by emphasizing recovery, wellness, and the importance of social determinants of health.⁸ They have become vital change agents in policy and strategic planning, as exemplified by the establishment of the National Association of Consumer/Survivor Mental Health Administrators.⁹



Benefits of Engaging with People with Lived Experience

In the 1990s, the South African disability rights movement introduced the phrase 'Nothing About Us Without Us'.¹⁰ The slogan emphasizes the importance of empowering people with disabilities by involving them in decisions that affect their lives. It also captures the core value of engaging people with lived experience in behavioral health transformation efforts. Based on evidence from various countries, the World Health Organization asserts that interventions involving and empowering individuals receiving care, caregivers, and families can enhance care quality, leading to more efficient health service utilization, cost reduction, and better outcomes.¹¹

Following are key benefits of engaging people with lived experience in behavioral health transformation efforts:

- **Greater understanding of the significant challenges faced by disadvantaged groups when accessing the behavioral health delivery system.** Individuals from historically marginalized groups have distinct lived experiences in seeking behavioral health services and support. They encounter disproportionately higher levels of unfair treatment, negative experiences, unmet mental health needs,

and poorer health outcomes.¹² It is important to hear directly from those with experience navigating the system to understand these challenges.

- **More responsive and equitable services, programs, and policies that meet the needs of affected communities.** When those directly affected by programs and policies actively participate in improving behavioral health practices, the resulting policies and programs are more sustainable and better aligned with community needs and priorities.¹³ Furthermore, engaging people with lived experience can assist state behavioral health agencies in deciding how to allocate resources and prioritize interventions and programs.¹⁴
- **Better assessment of individuals' experiences and satisfaction with behavioral health services and the impact of policies and programs from a community perspective.** Although numerous quality measures are used to assess the quality and outcomes of behavioral health care, these measures may not always accurately assess the goals, priorities, and perceptions of those receiving care. Engagement can offer a more comprehensive picture of how the system operates (or doesn't) for specific groups and a more nuanced look at how certain policies and programs impact affected communities. It can also shed light on what to measure, provide a deeper understanding of collected data, and reveal opportunities to address behavioral health inequities and enhance health outcomes.¹⁵
- **More trauma-informed practices and approaches to address discrimination and stigma.** Individuals with behavioral health conditions often face discrimination and stigma when accessing services and care. This can worsen their behavioral health problems, prevent them from getting the help they need, and lead to a distrust of the behavioral health system.¹⁶ Engaging people with lived experience builds trust within the community. It encourages state behavioral health staff to recognize existing implicit biases and apply trauma-responsive practices in their engagement processes as well as in program and policy development and implementation.
- **Improvement in individual engagement in services and supports.** Individuals needing behavioral health services often struggle to stay engaged in treatment due to dissatisfaction with care, discrimination, accessibility issues, and health-related social needs.¹⁷ This can exacerbate poor health outcomes and reduce opportunities for individuals to achieve their recovery goals.¹⁸ Meaningfully engaging individuals and families in program and policy design, implementation, and evaluation can help address these challenges, ultimately improving engagement in treatment and satisfaction with care delivery.

Refuting the Skeptics: Addressing Concerns in Engaging People with Lived Experience with Behavioral Health

While many states already have mechanisms like mental health or behavioral health planning councils to engage people with lived experience and expertise, some still face challenges enhancing their engagement practices or may not find them meaningful in broader behavioral health transformation efforts. This is partly because such engagement may require developing new processes and relationships, shifting internal culture, and investing more time in upfront planning. A key aspect of advancing this work is building support for engagement among critical stakeholders and decision-makers and addressing concerns about the process and its purpose.

Below are common concerns voiced by system leaders and messaging tips for addressing them.

CONCERN: *People with lived experience and expertise may have expectations we cannot fulfill. Without understanding organizational limitations, they may become disappointed, believing that the organization makes empty promises and is not committed to change.*

RESPONSE: If limitations of what cannot be accomplished are shared upfront and throughout the engagement process, people with lived experience would be more likely to understand limitations inherent in state government. Additionally, behavioral agencies can support them by providing education on how the agency operates, policy processes, and the interplay of systems. By being transparent and providing support, agency staff can build trust with people with lived experience and work collaboratively to identify approaches to expanding access to equitable services.

CONCERN: *Engaging people with lived experience cannot accurately reflect all those impacted.*

RESPONSE: Indeed, the behavioral health system is not experienced equally by everyone who receives services. People also come to the table with intersecting identities, resulting in unique experiences. This is why it is important to seek representation from diverse backgrounds to incorporate an array of experiences and expertise. Organizations may engage with the same people or with groups that are comfortable with the status quo, limiting opportunities for robust and diverse input. SAMHSA has developed best practices for recruitment to ensure representation, including: (1) broadening outreach beyond the mental health community by contacting local groups advocating for specific racial, ethnic, and other marginalized groups, such as the National Council on Asian Pacific Americans, the NAACP, and UnidosUS; and (2) sharing engagement opportunities on state websites, social media, email, and with outside organizations.¹⁹

CONCERN: *People with behavioral health challenges may not be equipped to weigh in on larger system issues. The expertise of system leaders, clinicians, and people with relevant degrees should guide system-level changes.*

RESPONSE: The crux of this concern lies in the stigma and assumptions of incompetence surrounding individuals with behavioral health needs and the belief that personal experiences cannot be translated into larger system work. The experience of navigating system services and supports is a valuable source of knowledge. Many states have recovery offices that successfully employ individuals with lived experience of mental health and substance use conditions. For instance, the Texas Health and Human Services Commission established a Peer and Recovery Services Unit that employs staff with lived experience of mental health and substance use disorders. These individuals guide the system toward a recovery-oriented approach by implementing programs and policies that enhance peer support and recovery services.²⁰ Pennsylvania established the Behavioral Health Commission for Adult Mental Health, which includes people with lived experience with behavioral health conditions alongside state agency leaders and other community and behavioral health representatives. These individuals play a crucial role in providing recommendations for funding across various areas such as workforce development, behavioral health payment rates, crisis services, and integration of behavioral health and substance use disorder treatment.²¹

CONCERN: *Engaging people with lived experience represents a significant shift in how the organization approaches program and policy design, implementation, and evaluation. This process can be expensive and time-consuming and may fail without adequate preparation and expertise.*

RESPONSE: Engaging people with lived experience does require an investment of time and resources. Yet, the cost of unaddressed behavioral health inequities and the delivery of ineffective supports and services may far exceed this initial investment.²² Investing time to listen and collaborate with people with lived experience, build trusting relationships, and establish equitable practices for meaningful engagement can be a substantial undertaking, but it is necessary to overcome the status quo. This investment will likely help lead to improved services, better health outcomes for those with behavioral health needs, and more effective programs and policies.²³ To plan appropriately, state behavioral health agencies can partner with community-based organizations and technical assistance providers specializing in organizational culture change and community engagement to navigate aspects of engagement.

CONCERN: *Sharing power and decision-making with people with lived experience will compromise leadership's ability to make decisions.*

RESPONSE: Communities experiencing high rates of behavioral health needs often feel disempowered due to systemic, social, and economic factors. Inviting them into policy and program discussions creates opportunities to rebuild community power by increasing access to decision-making at the state and local levels that impact their health outcomes and well-being. Sharing power with the people closest to the problems and solutions will enhance effective decision-making and responsive solutions within state behavioral agencies. It also increases buy-in from communities and behavioral health stakeholders for policy and programmatic decisions.

There is a continuum of community engagement approaches that state behavioral health agencies can employ to collaborate with people with lived experience, ranging from informing to consulting and collaborating.²⁴ While power-sharing is often associated with the most meaningful form of engagement, where community-led solutions are achieved, opportunities to share power exist at all levels of engagement. Sharing power begins with being intentional about developing equitable structures and processes that address power imbalances, create bi-directional exchanges of information, and ensure that communities can fully participate and have some degree of influence on the policies and programs they engage in.²⁵ Empowering those with lived experience to help guide system transformation ensures that solutions meet everyone's needs, are culturally responsive, and individualized, leading to meaningful improvements in access and service delivery.

The Importance of Leadership Champions in Engaging People with Lived Experience

For agencies seeking to transform behavioral health services, it is essential to have **organizational leaders who serve as champions**, steadfastly supporting the development of the engagement process with people with lived experience. Champions advocate to include people with lived experience in systems change efforts by creating platforms for meaningful involvement through advisory boards, committees, and, in some cases, paid positions. Additionally, they participate in community engagement meetings to model support for people with lived experience and invite discussions that build empowerment and trust. **Leadership champions** can hold employees and the systems that they oversee accountable, ensuring meaningful participation, and equitable organizational processes and compensation of people with lived experience. Furthermore, champions ensure that people with lived experience have the necessary resources and support to effectively contribute to program and policy design, implementation, and evaluation.

Without strong support from the top, efforts to engage meaningfully with people with lived experience may falter. **Securing leadership buy-in** to support meaningful engagement is essential in developing strong support, insulating against potential stakeholder backlash, and securing organizational resources to sustain effective engagement. This work can be disruptive by design and must be protected by leadership to ensure its success. While staff can advocate for collaboration with people with lived experience and establish engagement processes, efforts may stall if there is insufficient investment and prioritization at the organizational level, especially when competing priorities exist.

Additionally, if leadership and key decision-makers fail to communicate their support and demonstrate the value of this work, it may feel tokenizing to the individuals being engaged and more challenging to address power imbalances on a larger scale at the organization. Champions in leadership roles can catalyze internal culture change, fostering an organizational environment where engaging and partnering with people with lived experience is essential for shaping and improving services and policies.

Practical Strategies to Secure Leadership Buy-in for Meaningful Engagement with People with Lived Expertise

As discussed in the prior section, committed behavioral health agency leadership is essential for effective agency-wide approaches for engaging people with lived behavioral health experience. Following are strategies to garner leadership support and buy-in to engage people with lived experience in behavioral health transformation efforts.

1. Design and implement a comprehensive communication strategy.

Securing leadership buy-in begins with understanding what is important to that leader and helping them recognize the value of engaging people with lived experience. Here are key steps to consider when developing an internal messaging strategy to advocate for engaging people with lived experience to leaders within the state behavioral health agency:



- **Create opportunities for leadership to engage directly with people with lived experience and expertise** to hear their perspectives, being intentional about seeking diverse representation and mitigating power imbalances during those conversations. In facilitating those conversations, it may be helpful to identify an issue that the state agency is struggling with (e.g., engaging people with serious mental illness who are experiencing homelessness in services and supports) and have individuals with lived experience provide their insights on how the agency might address the issue. Creating space for leadership to engage directly with people with lived experience and hear their perspectives on potential solutions for their communities could accelerate gaining leadership support and open the door for more conversations and processes that involve people with lived experience.
- **Involve leadership in cross-perspective dialogue and collaboration.** Plan convenings, including leadership and relevant stakeholders from various sectors (peer-led organizations, health care, social service, criminal justice, etc.) to discuss the value of engaging people with lived experience in behavioral health efforts. Many leaders and policymakers do not understand what it truly means to co-produce or lead with people with lived experience. There needs to be space for ongoing dialogue and for all partners to define their “why” and the significance of partnering with the people they serve. Grounding practices in the principle of ‘nothing about us without us’ needs to be a priority for all stakeholders. These conversations can help shift leadership perspectives on the “why” to involve people with lived experience in behavioral health system transformation discussions.

- **Establish ongoing opportunities to engage with agency leadership and decision-makers.** Share the vision for engaging people with lived experience and emphasize the value of that engagement, drawing connections with organizational priorities (e.g., improving patient outcomes, lowering costs). Try to understand leadership perspectives and identify shared values to strengthen the case.
- **Incorporate return on investment (ROI) in messaging.** While conducting a cost analysis or calculating ROI can be challenging due to limited data, it is important to recognize that leaders have to consider the business case before involving people with lived experience and committing to such an investment. Highlight the potential financial benefits of improved health services and outcomes. Data obtained from the state or collected internally for quality improvement purposes can be used to argue the cost of poor outcomes for people receiving services, including avoidable hospitalizations and other high-cost, high-intensity services.²⁶

2. Make the case with examples from other state behavioral health agencies or organizations.

Part of making the case is demonstrating that meaningful engagement with people with lived experience is achievable. It is important to examine how other state agencies or organizations are actively working to bolster their engagement practices and explore various engagement models to encourage innovation. Consider the following key steps:



- **Share examples of meaningful engagement within state and local behavioral health agencies.** Focus on best practices that demonstrate the benefits of engaging people with lived experience in policy and program design, implementation, and evaluation. Here are a few examples to get started:
 - **The Office of Recovery Community Affairs within Connecticut’s Department of Mental Health and Addiction Services** has been revamping its peer support certification process. In partnership with the Yale Program for Recovery and Community Health and using a community-based participatory research model, they hosted a series of online forums to inform and gather input from the public about the development and implementation process, particularly from the recovery community.²⁷ As a result, hundreds of people with lived experience and expertise participated in these discussions and provided recommendations. This engagement ensured that people with lived experience significantly guided the design process of the peer support credentialing process.
 - Following the passage of HB 1477, **the Washington Health Care Authority, Department of Health, and Behavioral Health Institute** established the Crisis Improvement Strategy Committee and Steering Committee.²⁸ These committees aim to improve the state’s behavioral health crisis response and suicide

prevention services and guide the implementation of the national 988 suicide prevention hotline.²⁹ To ensure diverse representation and gather comprehensive recommendations, the Steering Committee formed seven subcommittees, including the **Lived Experience Subcommittee**. This subcommittee, composed exclusively of people with lived experience of behavioral health conditions, is responsible for reviewing implementation data to ensure the project meets community needs, sharing promotional and educational information within their communities, and providing recommendations to the Steering Committee to ensure the community informs decisions.³⁰

- **Seek opportunities to connect and learn from other agencies.** Consider reaching out to agencies identified to learn firsthand about their efforts and experiences. Alternatively, join a learning community that supports states in transforming their engagement practices.

3. Develop a strategic plan or roadmap to share with leadership.

Once the organizational priorities and values guiding leadership are clear and messaging is established to highlight the importance of engaging people with lived experience, it is essential to turn these into actionable steps. At this point, sharing a written plan with leadership is crucial to outline how the agency can progress toward the presented goals. Within the plan or roadmap, be sure to:



- **Establish goals and outcomes for engagement.** Convey the intended goals and outcomes of engaging people with lived experience in the agency's behavioral health efforts. Emphasize any alignment with agency goals and strategic priorities and explain how this approach promotes equity and supports overall objectives.
- **Develop clear guidance for getting started.** Create internal guidance on how the agency can prepare for engagement with people with lived experience. This may include resources or tools to conduct an agency-wide readiness assessment that helps to highlight strengths, resources, and critical barriers to promoting this approach. This assessment may reveal that the agency already has a mental health planning council, behavioral health planning council, or other committees that engage people with lived experience and their families. The next step would be to examine the processes of these councils or committees to determine the resources needed to scale engagement or leverage these groups for programmatic and policy discussions regarding broader behavioral health plans. It is also important to determine if the agency needs to provide staff training on key engagement topics (e.g., trauma-informed practices, internal culture change, and best practices for member engagement). Additionally, explore forming new partnerships with

peer-led organizations and project expenses for compensating people with lived experience involved in these efforts.

- **Align behavioral health agency goals with Medicaid on new federal rules for member advisory groups.** Provide recommendations on how the state’s behavioral health agency can coordinate with Medicaid to discuss the implementation of newly required Beneficiary Advisory Councils and Medicaid Advisory Committees. Both behavioral health and Medicaid agencies can benefit from structuring engagement processes around shared goals and adopting a unified approach. This plan can include joint meetings between the two agencies, coordination to ensure representation of community members with behavioral health and Medicaid experience across the Beneficiary Advisory Councils and behavioral health advisory councils, and sharing resources and data to maximize impact and collaboration.
- **Anticipate potential challenges and solutions to engagement.** Identify the potential challenges the agency may encounter when engaging people with lived experience and create a well-defined plan for managing these challenges. For example, how will the behavioral health agency assess progress, evaluate outcomes, and communicate the impact of engagement activities to justify continued investment? What are opportunities to secure funding and manage resources for engagement activities amidst competing priorities? Specifically, how will engagement activities be funded, and will these efforts be included in the agency’s budget each fiscal year?

Marching Ahead

Prioritizing engagement with people with lived experience to guide behavioral health transformation efforts offers an equitable pathway to impactful change within the behavioral health system. Once leadership and other key decision-makers commit to this change, the next step is to ensure that this commitment is reflected in the agency’s mission statement, values, internal policies, and operations. With increased support from CMS and SAMHSA, state behavioral health agencies can explore how to meaningfully engage people with lived experience in all aspects of program and policy planning, as well as research. Additionally, behavioral health agencies can start to broaden their current approaches to explore ways to incorporate lived experience into key management and supervisory roles, as well as governance bodies like boards and steering committees. When decision-makers represent the communities they serve, the behavioral health system becomes more responsive to community needs. This comprehensive approach can significantly improve the behavioral health delivery system and yield better outcomes.

Additional Resources for Engaging People with Lived Experience

Here are helpful resources to plan and/or implement these strategies:

- **[Organizational Readiness Assessment](#)** – This tool can help organizations evaluate their capacity and readiness to engage and partner with community members for social and systems change.
- **[Building a Relational Culture](#)** – This resource provides a helpful guide on practices that individuals and organizations can follow to transform their organizational cultures to be more community-oriented and relational.
- **[Disparities Impact Statement](#)** – This tool can be useful for building a strategy to identify and communicate disparities, as well as developing goals and action plans for stakeholder engagement.
- **[Creating Inclusive Meeting Space to Ensure Community Participation](#)** – This checklist outlines best practices to ensure inclusive meeting processes and spaces for effective community engagement and participation.
- **[Creating a Memorandum of Agreement](#)** – This tool provides guidance and a template to create a memorandum of agreement for agencies seeking to work together.
- **[Equitable Community Engagement Toolkit](#)** – This toolkit includes assessments, checklists, plans, and budget templates designed to promote equitable community engagement.
- **[Levels of Collaboration](#)** – This tool offers a comprehensive chart outlining four levels of collaboration: networking, cooperation, coordination, and full collaboration, illustrating the various ways stakeholders can collaborate.
- **[Community Member Engagement Resource Center](#)** – This resource center offers practical guidance to help Medicaid stakeholders engage community members in policy and program design development.



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 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*. KFF. <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/>
- ² Panchal, N., Hill, L., Artiga, S., & Hamel, L. 2024, May 23.
- ³ Substance Abuse & Mental Health Services Administration. (n.d.). *Community mental health services block grant*. SAMHSA. Retrieved August 28, 2024, from <https://www.samhsa.gov/grants/block-grants/mhbg>
- ⁴ Spencer, A., Roman, C., & Moses, K. (2024, April 24). *New federal rules for Medicaid advisory committees and beneficiary advisory councils*. Center for Health Care Strategies. <https://www.chcs.org/resource/new-federal-rules-for-medicaid-advisory-committees-and-beneficiary-advisory-councils/>
- ⁵ Ruter, T., & Swarbrick, P. (2010). *Consumer Involvement With State Mental Health Authorities*. National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA) and National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council. <https://www.nasmhpd.org/sites/default/files/Consumer%20Involvement%20with%20Persons%20with%20SMI%20Final%20Part%201...rev%282%29.pdf>
- ⁶ Unzicker, R. (2001). *Mental health advocacy, from then to now*. National Association for Rights Protection and Advocacy (NARPA). <https://www.narpa.org/reference/mental-health-advocacy-from-then-to-now>
- ⁷ Myrick, K., & del Vecchio, P. (2016). Peer support services in the behavioral healthcare workforce: State of the field. *Psychiatric Rehabilitation Journal*, 39(3), 197–203. <https://doi.org/10.1037/prj0000188>
- ⁸ Ruter, T., & Swarbrick, P. (2010).
- ⁹ *Division of Recovery Support Services*. (n.d.). National Association of State Mental Health Program Directors. Retrieved August 25, 2024, from <https://www.nasmhpd.org/content/division-recovery-support-services>
- ¹⁰ Charlton, J. I.: (1998). *Nothing about Us without Us: Disability Oppression and Empowerment*. University of California Press. <https://doi.org/10.1525/9780520925441>
- ¹¹ *Delivering Quality Health Services: A Global Imperative for Universal Health Coverage*. (2018). Geneva: World Health Organization. <https://iris.who.int/bitstream/handle/10665/272465/9789241513906-eng.pdf>
- ¹² Panchal, N., Hill, L., Artiga, S., & Hamel, L. 2024, May 23.
- ¹³ The Forum for Youth Investment. (n.d.). *A Framework for Partnering with People with Lived Experience*. Retrieved August 26, 2024, from <https://forumfyi.org/wp-content/uploads/2024/03/Partnering-with-PwLE-in-Systems-Change-2-28-24.pdf>
- ¹⁴ Skelton-Wilson, S., Sandoval-Lunn, M., Zhang, X., Stern, F., & Kendall, J. (2021). *Methods and Emerging Strategies to Engage People with Lived Experience Improving Federal Research, Policy, and Practice*. Office of the Assistant Secretary for Planning and Evaluation U.S. Department of Health and Human Services. <https://aspe.hhs.gov/sites/default/files/documents/62e7a64c60e10c47484b763aa9868f99/lived-experience-brief.pdf>
- ¹⁵ *Why engage community members in Medicaid policy and program design?* (2024, June 4). Center for Health Care Strategies. <https://www.chcs.org/resource-center-category/getting-started-with-community-member-engagement/>
- ¹⁶ American Psychiatric Association. (n.d.). *Stigma, prejudice and discrimination against people with mental illness*. Retrieved August 26, 2024, from <https://www.psychiatry.org/patients-families/stigma-and-discrimination>
- ¹⁷ Dixon LB, Holoshitz Y, Nossel I. Treatment engagement of individuals experiencing mental illness: review and update. *World Psychiatry*. 2016 Feb;15(1):13-20. doi: 10.1002/wps.20306. Erratum in: *World Psychiatry*. 2016 Jun;15(2):189. doi: 10.1002/wps.20372. PMID: 26833597; PMCID: PMC4780300.
- ¹⁸ Dixon LB, Holoshitz Y, Nossel I. 2016, Feb.
- ¹⁹ Substance Abuse and Mental Health Services Administration. (2023). *State behavioral health planning councils: An introductory manual*. <https://www.samhsa.gov/sites/default/files/planning-council-introductory-manual.pdf>
- ²⁰ *Peer support services*. (n.d.). Texas Health and Human Services. Retrieved August 26, 2024, from <https://www.hhs.texas.gov/providers/behavioral-health-services/providers/peer-support-services>
- ²¹ *Adult Mental Health Commission*. (n.d.). Commonwealth of Pennsylvania. Retrieved August 26, 2024, from <https://www.pa.gov/en/agencies/dhs/resources/mental-health-substance-use-disorder/adult-mental-health-commission.html>
- ²² Dunlap, N., Dawes, D., Bhatt, J., Amador, C., Rush, B., & Gebreyes, K. (2024, May 14). *The projected costs and economic impact of mental health inequities in the United States*. *Deloitte*. <https://www2.deloitte.com/us/en/insights/industry/health-care/economic-burden-mental-health-inequities.html>
- ²³ James, J. (February 14, 2013). *Patient Engagement*. Health Affairs Health Policy Brief. DOI: 10.1377/hpb20130214.898775

²⁴ Center for Health Care Strategies. (2024, June). *Engaging community members in Medicaid policy and program design*. [Fact sheet]. <https://www.chcs.org/media/Engaging-Community-Members-in-Medicaid-Policy-and-Program-Design.pdf>

²⁵ Everette, T., Sathasivam, D., & Siegel, K. (2023). *Transformational Community Engagement to Advance Health Equity*. State Health & Value Strategies. <https://www.shvs.org/resource/transformational-community-engagement-to-advance-health-equity/>

²⁶ Dunlap, N., Dawes, D., Bhatt, J., Amador, C., Rush, B., & Gebreyes, K. 2024, May 14.

²⁷ Connecticut State Department of Mental Health and Addiction Services. (2023). The Office of Recovery Community Affairs (ORCA). <https://portal.ct.gov/dmhas/divisions/divisions/recovery-community-affairs>

²⁸ Washington State Health Care Authority. (n.d). *Crisis Response Improvement Strategy (CRIS) committees*. <https://www.hca.wa.gov/about-hca/programs-and-initiatives/behavioral-health-and-recovery/crisis-response-improvement-strategy-cris-committees>

²⁹ Washington State Health Care Authority. (n.d).

³⁰ Washington State Health Care Authority. (June 2024). *CRIS Lived Experience Subcommittee meeting*. <https://www.hca.wa.gov/assets/program/cris-lived-experience-subcommittee-meeting-presentation-20240610.pdf>