KNOWLEDGE BITES

NO. 8: TRANSFORMING BEHAVIORAL HEALTH CRISIS SYSTEMS THROUGH AUTHENTIC COMMUNITY ENGAGEMENT

Background

Meaningful community engagement must be community-driven and authentic

Inequities in access to behavioral health care create long-term health disparities and can exacerbate behavioral health symptoms. Lack of access to comprehensive, trauma-informed behavioral health crisis services can result in unnecessary and traumatic contact with law enforcement, and increases the risk of incarceration, psychiatric boarding in hospital emergency departments, and even death. Racially and socially marginalized groups are disproportionately affected by ineffective behavioral health crisis responses. BIPOC individuals, particularly those who identify as Black or multiracial, are more likely to be involuntarily committed, and Black individuals experiencing psychosis are more likely to be incarcerated. As states reimagine their behavioral health crisis systems, they must work closely with communities that have experienced the greatest impact from system gaps and unequal access. The failure to adequately engage individuals with lived experience will continue to perpetuate harm and exacerbate disparate impacts.

After decreasing for a decade, the rate of death by suicide rose by 4% from 2020 to 2021, making suicide the second leading cause of death among people ages 10 to 34. Drug overdose deaths are rising precipitously, with particularly devastating results among African Americans, Latinx people, and American Indians and Alaska Natives. Nationwide, pediatric behavioral health emergency department (ED) visits have increased dramatically, particularly for youth with Medicaid or no health insurance. After initial assessment, youth will stay in the ED or be transferred to an inpatient medical unit until a bed becomes available at an inpatient psychiatric facility — sometimes hours, days, or even weeks later. Youth visits to the ED for psychiatric reasons are rising most quickly for Black and Hispanic/Latino youth.

"Typical" Community Engagement

Community engagement often consists of occasional community meetings, focus groups, or key informant interviews from which information is taken by those in power to inform the modification of a system. As a result, "typical" community engagement is not fully participatory. While this approach serves a distinct purpose, it is often not comprehensive, intentional, or diverse enough and can promote tokenism. "Typical" community engagement often lacks shared decision-making with the people most affected. In addition, it is often time-limited, inaccessible, and does not engage community partners throughout the development and implementation process. Meaningful community engagement must be community-driven and authentic.

Authentic Community Engagement

To meaningfully transform the behavioral health crisis system, states must engage in authentic community engagement — a two-way dialogue between crisis-impacted communities and system agents (State Behavioral Health Authorities, crisis providers, Medicaid Authorities, law enforcement

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agencies, etc.) that involves shared power and decision-making. Authentic community engagement also involves engaging and drawing on innate community assets, resources, and knowledge to co-create an informed system and strategy. In shared decision-making, system agents and intended service recipients work together with equal power and influence.

Barriers to Authentic Community Engagement

BARRIER TO COMMUNITY ENGAGEMENT	HOW THIS BARRIER MAY PRESENT
Insufficient funding	Real or perceived competition for resources
Time constraints	Strict legislative mandates
Liability-based system/Paternalism	Sanction-based systems and care
Status quo	Aversion to change and innovation
Bias and discrimination	Racism/sexism/ageism/ableism/etc.
Lack of coordination	Siloed systems
Incongruent values	Competing goals and objectives
Diffused responsibility	Poorly defined roles
Lack of intentional trust building	Historical trauma and victimization
Lack of recognition	Power imbalances and top-down decision making
Tokenism	A single person representing a racially or socially marginalized group
Polarization	Divergent opinions, beliefs, and values

State Recommendations to Support Authentic Community Engagement

1. Incorporate diverse lived experience into the design, implementation, and oversight of crisis systems. Ensure governance structure reflects the diversity of the community and allows people with lived experience (PWLE) a real voice in decision-making.
2. Compensate PWLE appropriately, and take steps to ensure stakeholders are accessible (meetings during non-business hours, support with childcare or transportation, language accessibility etc.).
3. Evaluate community outreach strategies to target underrepresented populations. Explore options for peer-to-peer outreach, credible messengers, and in-person outreach and engagement.
4. Invest in community engagement, input, and healing. Identify alternative funds to support authentic and sustained community engagement.

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Additional Resources

- **U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation**
  Methods and Emerging Strategies to Engage People with Lived Experience
- ***Nonprofit Quarterly Magazine***
  Collaborating for Equity and Justice: Moving Beyond Collective Impact
- **Centers for Disease Control and Prevention, Agency for Toxic Substances and Disease Registry**
  Community Engagement: Definitions and Organizing Concepts from Literature
- **Lived Experience Advisory Council**
  Nothing About Us Without Us: Seven Principles for Leadership & Inclusion of People with Lived Experience of Homelessness
- **World Health Organization** WHO Framework for Meaningful Engagement of People Living with Noncommunicable Diseases, and Mental Health and Neurological Conditions