

INSPIRE's Community Engagement Learning Network

Session #16: How healthcare organizations and people with lived experience can work together to save Medicaid: A case study from Utah.

Featured presenters: [Protect Medicaid Utah Coalition](#)
September 2026

Every month, the Community Engagement Learning Network will bring together a nationwide team of community engagement (CE) professionals and people with lived experience to host group discussions about improving CE efforts, present best practices for launching and maintaining CE initiatives — drawn from experts in the field, and foster community-building among participants.



Key takeaways

- People with lived experience should be engaged as equal partners in advocacy and problem-solving, not only as storytellers.
- Integrated engagement means creating multiple pathways for participation from the beginning. People with lived experience can contribute through leadership roles, peer groups, public testimony, town halls, advisory committees, organizing, and other forms of participation that recognize different interests, capacities, and levels of engagement.

- Finding mutual benefit can bring unexpected partners to the table. Understanding what matters to different stakeholders - including healthcare providers, people with lived experience, government, local leaders, and other community partners - can reveal shared interests and create opportunities for collaboration across traditional boundaries.
- Impact can take many forms. Advocacy efforts may not always produce the desired policy outcome, but they can still create meaningful change by elevating lived experience, building relationships, influencing decisions, preventing harmful changes, or increasing people's confidence and ability to participate in civic life.
- Organizations can strengthen their collective ability to address an issue when they view one another as partners rather than competitors for limited resources or attention.



Action steps

Treat people with lived experience as equal partners

- Move beyond using lived experience primarily to illustrate a problem. Create a variety of opportunities for people with lived experience to participate in defining problems, developing solutions, setting priorities, and determining how advocacy efforts should move forward.
 - Not everyone will want or be able to take on the same role, and meaningful engagement can include leadership positions as well as lower-barrier opportunities to contribute.
- Consider whether people with lived experience have meaningful influence within your organization's advocacy or policy work. Ask:
 - Are people with lived experience involved early enough to shape the work?
 - Are they treated as equal partners in decision-making?
 - Are their ideas and expertise valued alongside professional or organizational expertise?
 - Are there opportunities to participate beyond sharing personal stories?
- Avoid tokenizing people with lived experience or relying on them primarily to share traumatic experiences. Take an asset-based approach that recognizes the knowledge, skills, relationships, and perspectives people bring beyond their personal experiences with a system.

Identify mutual benefit and build relationships across differences

- Begin coalition-building conversations by identifying what matters to each potential partner. A simple exercise such as a Venn diagram can help organizations and individuals identify areas where their interests overlap.
- Ask potential partners what the issue means for the people and communities they serve. Shared interests may emerge even when organizations have different missions, constituencies, or perspectives.
- Look beyond the organizations and stakeholders that traditionally participate in healthcare policy conversations. Consider who else is affected by the issue and who may have influence, expertise, relationships, or resources that could contribute to the work.
- Build relationships before you need them. Trust developed through previous collaboration can make it easier to navigate disagreements and identify common ground when new policy or organizational challenges arise.
- Recognize that effective coalitions do not require complete agreement. Develop the capacity to acknowledge different perspectives and interests while identifying areas where partners can work together.

Define, document, & celebrate your impact

- Define impact broadly. In addition to changes in policy or organizational practice, consider whether engagement:
 - Increased the visibility of lived experience
 - Influenced how an issue was understood
 - Created new relationships or partnerships
 - Prevented or reduced potential negative impacts
 - Increased people's confidence or sense of agency
 - Created opportunities for people to participate in civic life
- Help people understand how their participation connects to broader decision-making. When participants can see where their voices fit within a process, they are better positioned to determine how and when they want to participate.
- Recognize the personal impact of engagement. Meaningful engagement can be empowering, fulfilling, and contribute to personal wellbeing, growth, and development.

Think ‘outside the box’ by centering community engagement and advocacy

- Connect community engagement and government relations teams where possible. Patient or community advisory groups can work with government relations staff to identify issues that matter to members and develop advocacy projects together.

- Create opportunities for PWLE to participate in civic life beyond formal advisory structures, such as: candidate forums, town halls, community conversations, public hearings, and opportunities to connect with advocacy organizations.
- Meet people where they are. Opportunities for engagement can be created in settings where people already gather, including healthcare organizations, resource fairs, community events, and other trusted community spaces.

Build broad coalitions while maintaining a shared focus

- Start small. Beginning with a few trusted partners, identifying shared interests, and exploring one issue can create a foundation for broader collaboration.
- Consider whether your existing coalition reflects the full range of stakeholders affected by the issue. Ask who is missing and whose participation could add a different perspective, relationship, or form of influence.
- Focus conversations on concrete concerns and shared outcomes rather than assuming that stakeholders must share the same underlying motivations.
- Recognize that building broad coalitions requires ongoing relationship-building. New partnerships may begin with a single conversation or shared concern and develop over time as participants gain familiarity and trust.

“Truly integrated community engagement starts from the beginning, and not just as an afterthought.”



Resources for additional learning

- [Understanding the impact and outcomes of engaging PWLE - The Center to Advance Consumer Partnership](#)
- [Creating engagement opportunities - The Center to Advance Consumer Partnership](#)
- [Chapter 5., Section 5. Coalition Building I: Starting a Coalition - Main Section | Community Tool Box](#)

inspire partners

Organizations



People with lived experience



Alan
Coker



Burt
Pusch



Laura
Carroll



Rebecca
Esparza



Savina
Makalena



Stephanie
Burdick