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Elevating Community Voice in Shaping Medicaid Priorities

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Medicaid and the Children's Health Insurance Program (CHIP) provide access to critical health care services for low-income families, children, seniors, and people with disabilities. Serving nearly 80 million Americans, these programs are deeply embedded in the lives of real people. As such, the voices of individuals and families who rely on Medicaid are critical to shaping priorities and improving outcomes.

Effective delivery systems and benefit designs require a clear understanding of the needs and experiences of Medicaid members. Engaging individuals and families offers a direct window into the barriers they face accessing care — from transportation challenges and confusing eligibility rules in culturally appropriate services. Listening to those receiving services can help agencies refine programs in ways that purely quantitative data alone cannot provide. States have long recognized the importance of elevating member voices — and recent [Centers for Medicare & Medicaid Services' requirements](#) mandating the creation of Beneficiary Advisory Councils further underscore the need for robust engagement strategies that center the expertise of members and their families.

As Erin Peterson, parent advocate and member of the North Dakota Cross-Disability Advisory Council put it, *"Families [are] able to provide the face and story to who the state is supporting."* That statement captures an important truth: individual and family input is not just "nice to have" — it is central to a responsive and resilient Medicaid program.

From Policy to Practice: How Lived Experience Drives Change

Beyond helping to fine-tune policy, individual and family input fosters greater access to care and supports that meet individuals' health care needs. When people share what's working and what's not, Medicaid agencies can focus resources where they are needed most. That might mean increasing access to behavioral health services, improving home- and community-based services, or streamlining enrollment processes.

Culturally appropriate care — for example traditional healing practices for American Indian and Alaska Native populations — is another area where individual and family input makes a profound difference. Programs and policies are more likely to meet people where they are — linguistically, geographically,

and culturally — when guided by those who use them. This kind of responsiveness builds trust and ultimately improves health outcomes.

This principle came to life in powerful examples shared during recent episodes of the [Medicaid Leadership Exchange](#), a podcast hosted by the National Association of Medicaid Directors and the Center for Health Care Strategies with support from the Robert Wood Johnson Foundation:

- **North Dakota:** Erin Peterson, a family advocate, emphasized how family input helped the state cut through the complexities of its Medicaid program and focus on what would have the greatest impact on families. Families helped reframe the discussion from system-level changes to individual-level impact, allowing the state to set clearer priorities.
- **Utah:** Josip Ambrenac, director for the state’s Office of Long Term Services and Supports, reflected on the transformative role that parents play. *“There are probably no better advocates for a child than their parents. It is parents that end up being the catalyst for change.”* In Utah, family advocacy shaped policies that better support children with complex needs.

Common Challenges When Integrating Community Voice into Policy

Despite its importance, meaningful engagement of individuals and families is not without its challenges.

- **Time and resource constraints** often prevent Medicaid agencies from conducting robust outreach and relationship building. Staff may be stretched thin, and there may be limited funding and time for engagement activities.
- **Language and accessibility barriers** can impede participation, especially for individuals with limited English proficiency or those lacking access to technology or transportation. If engagement isn’t designed with these needs in mind, entire communities can be left out of the conversation.
- **Lack of trust** is another obstacle. Some communities have experienced systemic neglect or harm, making them understandably cautious about engaging with government entities. Building trust requires long-term investment and consistent follow-through.
- **Variation in community interests** adds further complexity. Different populations may have conflicting priorities, and no single solution will satisfy everyone.
- **Balancing member input with political and budgetary realities** is an ever-present tension. State agencies operate within complex political contexts and not all suggestions

can be implemented immediately. Still, involving members in identifying priorities and trade-offs fosters shared understanding and ownership.

Strategies to Strengthen Community Engagement and Build Trust

Despite these challenges, there are actionable strategies Medicaid agencies can adopt to strengthen member engagement:

- **Partner with members to co-design engagement processes**, including developing charters or bylaws for advisory groups. This helps ensure that the structure itself reflects members' needs and values.
- **Use outside facilitators or consultants** to guide discussions and maintain neutrality, especially in complex or emotionally charged conversations.
- **Make participation easier** by offering meetings at convenient times, allowing virtual attendance, and asking about accessibility or language needs in advance.
- **Amplify member and family stories** by inviting individuals to share their experiences directly with policymakers. Personal narratives often carry more weight than statistics in decision-making forums.
- **Be transparent** about what is possible — and what is not — to help manage expectations. Even when a specific request can't be accommodated, acknowledging it and communicating next steps demonstrates respect and helps build ongoing engagement.
- **Work with trusted community organizations** that have established relationships with Medicaid members. These partners can serve as bridges, translating policy into real-life context and encouraging participation.

Elevating the voices of individuals and families does more than improve Medicaid policy — it strengthens communities. When people feel heard and see their feedback reflected in decisions, they are more likely to engage, advocate, and participate in their own care. It also promotes a sense of shared purpose among policymakers, providers, and beneficiaries.

As evidenced in the sentiments expressed by Erin (ND) and Josip (UT), integrating individual and family input into priority setting is no longer viewed as a simple compliance activity carried out to meet federal or state regulatory expectations. It is central to ensuring that state Medicaid agency strategic priorities genuinely reflect the needs of those served by the program.

Kat Barchenger, Children's Waiver Administrator for the North Dakota Medicaid program, captured it best. According to Kat, when it comes to integrating the individual and family voice into priority setting, success means the focus *"moves away from how to get a program going to how to help a family."* That shift — rooted in empathy, collaboration, and community — is essential to the heart of all Medicaid transformation efforts.